

Exploring the guidance and attitudes regarding infant feeding options provided by Healthcare workers (HCWs) to HIV positive mothers of infants 0 – 12 months of age in South Africa

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Key Words

infant feeding

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policy implementation

Abstract

South Africa's Infant and Young Child Feeding (IYCF) policy guidelines of 2013 and its 2017 amendments recommend that mothers, including those living with HIV, exclusively breastfeed their infants until 24 months of age, followed by their gradual weaning. The 2013 changed policy guidelines occurred to align with global WHO recommendations of six-month exclusive breastfeeding for all HIV positive mothers, and consequently no longer recommended free formula feed as an option for HIV-positive mothers attending public sector services, except in limited circumstances. Despite these policy guidelines, less than a third of South African mothers exclusively breastfeed their infants. The other two thirds of mothers either formula feed or mixed feed their infants. Mixed feeding or exclusive breastfeeding by HIV positive mothers who have either not been on antiretroviral therapy (ART) long enough or are insufficiently adherent to ART to suppress their viral loads, can potentially lead to increased risk of Mother to Child Transmission (MTCT) of the Human Immunodeficiency Virus (HIV). Since healthcare workers (HCWs) play a key role in promoting the IYCF policy guidelines and encouraging its practice among HIV-positive mothers, it is crucial to determine the extent to which HCWs understand and subscribe to this important policy.

Using purposeful sampling and in-depth qualitative interview techniques, this qualitative study explored the attitudes of HCWs towards different infant feeding options, especially for HIV positive mothers, against the background of their understanding of the changes in IYCF policy guidelines between 2013 and 2017. The participants in this study included ten HCWs selected from three primary health care facilities in Khayelitsha (Western Cape, South Africa), and two programme coordinators based at the Western Cape's Department of Health Khayelitsha substructure office. By interviewing this diverse sample of HCW cadre, the study aimed to

explore their perceptions related to the factors which facilitate IYCF policy implementation versus those that hinder the implementation of this policy.

The findings revealed that HCWs interviewed had good overall familiarity with the IYCF policy guidelines. However, their depth of understanding and acceptability of the policy varied, especially in the context of high HIV MTCT risk. Suboptimal implementation of the policy occurred due to inadequate policy dissemination, diverse views on the limitations of the policy, such as the promotion of only exclusive breastfeeding as an option and an unclear rationale for recent policy changes. Additionally, HCWs high workload and insufficient training on the changed 2017 guidelines were identified as barriers to effectively implementing the new infant feeding policy guidelines. HCW further perceived that personal, socio-cultural and health system factors influenced new mothers' decisions and/or ability to breastfeed.

These findings highlight that improved policy dissemination strategies and training should be used to increase HCWs knowledge regarding infant feeding counselling content, including HIV MTCT risk. Western Cape Department of Health alignment and implementation of relevant National Department of Health HIV policies should occur to decrease MTCT risk while breastfeeding. Peer support groups could provide maternal support for continued postnatal ART adherence and for sustained safer feeding practices. Finally, while exclusive breastfeeding is the optimal feeding choice generally for mothers, future revision of the 2017 IYCF policy should consider allowing HCW to act more flexibly in the maternal guidance they provide on infant feeding options. This could allow greater discretion for HCW in infant feeding counselling of mothers, particularly for those women who are HIV positive. This would promote improved patient-centred counselling that takes into account both maternal socio-cultural context and the right to make individualised decisions regarding infant feeding.

Declaration of originality

I declare that this mini thesis, “Exploring the guidance and attitudes regarding infant feeding options provided by Healthcare workers (HCWs) to HIV positive mothers of infants 0 – 12 months of age” is my own work and has not been submitted for any degree or examination at another university. All the sources I have used or quoted have been indicated or acknowledged by way of complete references.

Erin Roberts

Signed



11 March 2021

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List of abbreviations

AFASS	Affordable, Feasible, Acceptable, Sustainable and Safe
ANC	Antenatal Care
ART	Antiretroviral therapy
BANC	Basic Antenatal care
BFHI	Baby Friendly Hospital Initiative
EBF	Exclusive Breastfeeding
EFF	Exclusive formula feeding
EID	Early Infant Diagnosis
FGD	Focus Group Discussion
HCWs	Healthcare workers
HIV	Human Immunodeficiency Virus
IYFP	Infant and Young Child Feeding Policy
LDL	Lower than Detection Limit
MOU	Maternity Obstetric Unit
MTCT	Mother to Child Transmission
PEP	Post Exposure Prophylaxis
PrEP	Pre-Exposure Prophylaxis
PHC	Primary Health Care
PMTCT	Prevention of Mother to Child transmission
SADH	South African Demographic and Health survey
UNICEF	United Nations International Children's Education Fund
VL	Viral Load
WCDoH	Western Cape Department of Health
WHO	World Health Organisation

Chapter One: Introduction

1.1 Background

The recommended optimal infant feeding practices for HIV positive women have evolved over time. HIV was first detected in breast milk in 1985. Initial World Health Organization (WHO) recommendations were that breastfeeding should continue to be promoted, supported, and protected in both developed and developing countries. The risk of infant death from HIV transmission was regarded as smaller than the risk of death if breast milk was withheld (WHO, 1987). In 1997, the global infant feeding recommendation changed to early cessation or avoidance of breastfeeding if formula feeding was “acceptable, feasible, affordable, sustainable and safe” (WHO, 2001:12). Higher income countries therefore recommended formula feeding for all HIV exposed infants to negate the risk of HIV transmission, while many middle- and lower-income countries recommended breastfeeding unless the formula feeding option met the recommended criteria outlined above. The South African infant and young child feeding (IYCF) policy implemented from 2002 to 2007 discouraged HIV positive mothers from breastfeeding due to the risk of Mother to Child Transmission (MTCT) (Mphasha & Skaal, 2018). In 2010, the WHO recommendations changed again after considering the improved access to Antiretroviral Therapy (ART) worldwide. The promotion of exclusive breastfeeding (EBF) for all HIV positive mothers, with the introduction of complimentary feeding from six months of age until 12 months of age, became the global recommendation. Emerging evidence of maternal viral load (VL) suppression while on ART and subsequent decreased risk of HIV MTCT, underpinned the changed recommendations (WHO, 2010). Between 2001 and 2010, exclusive formula feeding (EFF) was a feature of the Prevention of Mother to Child Transmission (PMTCT) policy in South Africa. During this period, formula feeding was regarded as optimal for HIV exposed infants in South Africa (du Plessis et al., 2016). In 2010, the PMTCT policy was changed to align with the recommendation of the WHO EBF for all infants, regardless of HIV status. In 2013, the revised Infant and Young Child Feeding (IYCF) policy changed their recommendations to align with global WHO recommendations of six-month EBF for all HIV positive mothers, with the continuation of complimentary feeding and breastfeeding until 12 months (South African National Department of Health, 2013).

Cornerstone to the changing global and local feeding policies is access and adherence to lifelong maternal ART. Since the implementation of the 2010 PMTCT guidelines, the risk of MTCT in HIV positive women in the Western Cape has decreased to less than 1% (Poolman,

van der Walt & Luwaca, 2017). However, a residual risk of MTCT does remain, and is one potential factor which may influence healthcare workers' (HCWs) infant feeding counselling. Furthermore, limited global and local infant feeding recommendations exist for HIV positive mothers who are at high risk of MTCT.

The practical implementation of the infant feeding recommendations and policies depends on a complex combination of factors. HCWs play a central role in the complex social ecology of how infant feeding decisions are made (Hector et al., 2005; Janse van Rensburg, Nel and Walsh, 2016; Nigel C Rollins et al., 2016). HCWs with the necessary knowledge and skills have the potential to support HIV positive mothers who adhere to EBF, despite family and social pressures. Similarly, HCW confusion surrounding multiple changes to the infant feeding recommendations and risk of MTCT, can confuse mothers and contribute to suboptimal practices, with inconsistent and misinformed guidance (Sibeko et al., 2009; Tuthill, McGrath and Young, 2014; Jama et al., 2017).

1.2 Problem statement

Despite the remarkable decline in paediatric HIV incidence worldwide, more than 150 000 children were infected with HIV in 2015, with 85% of them living in sub-Saharan Africa (UNICEF, 2016). Even though the primary mode of transmission for these occurred through breastfeeding, the recommended global and local infant feeding policy for all HIV exposed infants who are less than six months, remains exclusive breastfeeding (UNICEF/WHO, 2017). Despite these recommendations and changes to local policy, only 32% of South African infants younger than six months are reportedly EBF (NDoH et al., 2017). This may increase the risks of vertical HIV transmission through unsafe infant feeding practices. Healthcare workers (HCWs) have the potential to significantly influence the feeding choice of a mother. The HCWs role in influencing maternal infant feeding decisions, is well documented (Doherty et al., 2020; Fjeld, 2008; Horwood et al., 2019). Their advice can either contribute to sub-optimal infant feeding practices that may incur greater risk of MTCT of HIV or effectively increase EBF rates, which would protect against MTCT (Piwoz et al., 2006). HCWs who are not up to date with information, confused about the messaging or distrust the guidelines, may provide inaccurate information to patients. This could result in feeding practices that do not mitigate MTCT risk (Vallely et al., 2013). Limited research is available regarding HCW attitudes towards infant feeding counselling among high risk HIV positive mothers, hence the need for further research. Potential gaps in knowledge regarding relevant policies, breastfeeding advantages and MTCT risk, may undermine the steps taken to optimise infant health, and by

extension, community health. Further qualitative research among HCWs in clinical settings is required to promote our understanding and knowledge on this topic.

1.3 Study purpose

This study's purpose was to investigate HCW attitudes, views and knowledge of infant feeding advice provided to mothers living with HIV, and to inform public health research and practice.

The research for this master thesis was part of a broader qualitative study conducted in Cape Town by the School of Public Health at the University of the Western Cape (UWC).

1.4 Thesis aim and objectives

Aim

To explore the attitudes of healthcare workers towards infant feeding options, perceptions of facilitators, barriers, and guidance provided to HIV positive mothers concerning safe infant feeding practices for infants less than 12 months of age.

Objectives

1. To explore healthcare workers' knowledge of and attitudes towards the current infant feeding policy changes for HIV positive women.
2. To explore the infant feeding advice given to HIV positive women who are virologically suppressed and unsuppressed.
3. To explore healthcare workers' views on women's ability to implement the infant feeding advice provided and potential barriers or facilitators to them implementing this advice.
4. To formulate recommendations in order to contribute to improved HCW knowledge and implementation of the infant feeding policy to reduce MTCT risk.

1.5 Mini Thesis outline

Chapter 1. Introduction: The first chapter discusses the study background, provides a research problem statement, and describes the study's purpose, aim and objectives.

The remainder of the thesis consists of the following chapters:

Chapter 2. Literature review: This chapter presents the global and local literature relevant to the study topic. Literature regarding the advantages of breastfeeding for an infant, as well as the steps taken in South Africa to increase the rate of exclusive breastfeeding, is reviewed.

Furthermore, literature surrounding the relevant policies associated with prevention of HIV Mother to Child transmission, is reviewed, including the South African Antiretroviral treatment policies and the infant feeding policies. Rollins et al., (2016) conceptual framework is utilised to systematically present factors influencing an enabling breastfeeding environment for women. Lastly, literature regarding postnatal MTCT risk during infant feeding, is reviewed.

Chapter 3. *Methodology*: This chapter explains the study's research design, the research approach and methodology utilised. It describes the study setting, its population, the sampling and participant recruitment processes, the data collection and analysis and the study's ethical considerations.

Chapter 4. *Findings*: This chapter provides a demographic profile of participants and presents the key themes that emerged in the research findings.

Chapter 5. *Discussion*: This chapter discusses and interprets the study findings. It highlights the similarities and differences between this study's findings and those of other studies. It also discusses the study's limitations.

Chapter 6. *Conclusions and recommendations*. This final chapter presents the study conclusions. In addition, it presents four key recommendations aimed at enhancing infant feeding advice offered in the South African public healthcare sector to pregnant mothers living with HIV.

Chapter Two: Literature Review

2.1 Introduction

This chapter provides an overview of the evolving infant feeding policies in South Africa and how they align with global recommendations for Prevention-of-Mother-to-Child-Transmission of HIV (PMTCT). It provides a review of relevant literature related to 1) paediatric HIV incidence globally and locally; 2) the advantages of breastfeeding; 3) the prevalence of exclusive breastfeeding both globally and locally; 4) the journey of the PMTCT program since its implementation in South Africa; 5) the factors influencing infant feeding practices in the first six months of life, including HCW and policy translation and lastly 6) the risk of Mother-to-Child Transmission of HIV (MTCT).

2.2 HIV incidence in children

A 60% reduction in global HIV paediatric infections occurred between 2000 and 2018, with infections falling from 450 000 to 160 000 (Slogrove et al., 2020). The majority of current MTCT infections are postnatal transmissions that occur in the first six months of the infant's life (Goga et al., 2016), making this a critical period during which there is HIV MTCT risk through infant feeding.

Prior to global PMTCT interventions, including maternal ART, the risk of mother to child HIV transmission was 25% to 35% (Newell, 2003; Read, 2004). Since the introduction of PMTCT strategies, the risk of MTCT has significantly decreased. A systematic review of 11 global studies found the risk of HIV MTCT while breastfeeding and on maternal ART to be 1.08 (95% CI: 0.32–1.85) at six months of age and 2.93 (95% CI: 0.68–5.18) at 12 months (Bispo et al., 2017). However, if mothers are virologically suppressed on ART, the estimated HIV transmission rate is reduced to 0.2% per month of breastfeeding postnatally (Rollins et al., 2012). This corresponds to an expected residual MTCT rate of 2.4% at 12 months of breastfeeding (Van de Perre et al., 2017).

As a result of implementing these overall global PMTCT recommendations, South Africa witnessed an over 80% reduction in annual HIV paediatric infections, with an estimated 10 000 paediatric infections occurring in 2019 (UNAID, 2020).

Despite breastfeeding currently being the primary mode of paediatric HIV infections, albeit it with a lower risk than previously, exclusive breastfeeding is the WHO recommended infant feeding choice for HIV exposed infants younger than six months (WHO, 2010). In keeping with

WHO recommendations on breastfeeding, South Africa adopted the 2011 Tshwane Declaration and the 2013 Infant and Young Child Feeding (IYCF) policy. Both promote and support exclusive breastfeeding for all infants younger than six months, including HIV exposed infants. Understanding the benefits of breastfeeding, as well as the HIV risk, is pertinent to HCW infant feeding counselling.

2.3 Breastfeeding: Infant development in the first 1000 days

The first 1000 days of an infant's life is a critical window period to ensure that children survive and thrive. Children who receive the right nutrition during this period are more likely to overcome critical illnesses and reach healthy adulthood (UNICEF, 2017). A review of the importance of exclusive breastfeeding is pertinent to this study and forms the cornerstone of the infant feeding policy being studied.

Exclusive breastfeeding for the first six months is recognised as the most effective intervention to achieve optimal growth and development of infants (WHO, 2013). More than 25 years ago, the WHO released a statement which read that breastfeeding is an “unequalled way of providing ideal food for the healthy growth and development of infants” (WHO, 1989:3). Critical brain circuits responsible for future complex tasks and behaviours are laid down during this period of neurodevelopment. The unique micro and macro nutrients found in breast milk provide the optimal food for brain development (Schwarzenberg and Georgieff, 2018). Half of all diarrhoeal cases and nearly one-third of all respiratory infections in middle and low income countries could be prevented by improving breastfeeding practices (WHO, 2017). Although the short and long term benefits of breastfeeding are well documented in scientific literature (Horta and Victora, 2013; Binns, Lee and Low, 2016), confusion among HCWs on how best to advise and support mothers to achieve these benefits has been documented. However, literature on this is limited (Piwoz et al., 2006; Janse van Rensburg, Nel and Walsh, 2016) .

2.4 Breastfeeding in South Africa: A public health concern

Global concern regarding diminishing breastfeeding rates culminated in the 1990 UNICEF ‘Innocenti Declaration’, which affirmed that for optimal health “all women should be enabled to practice exclusive breastfeeding and all infants should be fed exclusively on breast milk from birth to 4 – 6 months of age”(UNICEF, 2005:viii). The ‘Baby Friendly Hospital Initiative’ (BFHI) of 1991 was launched to further protect, promote and support successful breastfeeding globally (UNICEF/WHO, 2009). Despite these global initiatives implemented nearly 28 years

ago, the rate of exclusive breastfeeding worldwide in infants less than six months old is only 40% (UNICEF/WHO, 2017).

The 2016 South African Demographic and Health Survey (SADHS) found that only 32% of infants under the age of six months are exclusively breastfed. While this is a significant increase from the 7% infants exclusively breastfed in 1998, it fails to reach the recommendation that all infants less than six months should be exclusively breastfed (NDoH et al., 2017). Multiple contributing factors influencing the acceptability or unacceptability of EBF among Southern African women have been identified in literature. This includes fear of MTCT among HIV positive women (Husain Rasheed et al., 2018; Doherty et al., 2012; Bekere, Garoma & Beyene, 2014).

Low EBF rates not only are a concern for individual infants, but also for the health of the South African population. There is increasing evidence regarding the long-term protection against chronic disease offered by breastfeeding. Infants who are breastfed and mothers who breastfeed, have lower rates of obesity. Other chronic diseases that are reduced by breastfeeding include diabetes, hypertension, cardiovascular disease, hyperlipidaemia and some cancers (Binns, Lee and Low, 2016; del Ciampo and del Ciampo, 2018). The WHO has set long-term nutrition targets to be reached by 2025, including increasing EBF practice by 50% of mothers in the first six months of life (WHO, 2014). In order to achieve this 50% target, between 100 000 to 200 000 South African mothers— who are currently not breastfeeding, would need to be supported and encouraged to become breastfeeding mothers by 2025 (Martin-Wiesner, 2018). It is therefore essential to understand not only the advantages of breastfeeding, but also the multifaceted determinants of EBF to achieve this target. A positive HIV status and MTCT risk are additional factors faced by many women in South Africa in their decision-making on infant feeding, where the HIV prevalence is approximately 30% among pregnant women (Woldesenbet et al., 2019).

There is limited evidence on the percentage of HIV negative compared to HIV positive women who successfully practice EBF in South Africa, as this data is not routinely collected. However, two separate studies conducted in Johannesburg found that HIV negative participants reported higher rates of EBF compared to HIV positive participants. Additionally, the intent to breastfeed was higher among HIV negative participants in both studies (West et al., 2019; Mnyani et al., 2016). Although HIV is a contributing factor to the infant feeding decision, the extent to which it influences a woman's feeding choice is difficult to determine. Therefore

accurate and consistent messaging regarding HIV and breastfeeding needs to be provided to HIV infected, women, those of unknown HIV status and uninfected women, so as to diminish HIV as an influencing factor in infant feeding choices.

2.5 Prevention of MTCT: The journey towards elimination of mother to child transmission

South Africa officially launched its HIV PMTCT programme in 2004, and has continued to amend policies and approaches to curb the incidence of vertically infected infants (Sherman et al., 2017). In the section below, relevant policies, their implementation and the achievements of the PMTCT program, are reviewed. However, to achieve complete elimination of MTCT, the gaps in the journey, including the challenges HCWs face with the implementation of the infant feeding policy, need to be recognised.

2.5.1 Antiretroviral therapy policies

In 2015, the South African Department of Health amended PMTCT guidelines, making provision to increase antiretroviral (ART) coverage so as to provide lifelong ART for all HIV-positive pregnant and breastfeeding women (PMTCT Option B+) (South African National Department of Health, 2015). Reduction in maternal viremia is the goal of the triple antiretroviral therapy provided to pregnant and post-natal women, thus dramatically lowering the risk of HIV MTCT (Myer et al., 2017b). Timely ART initiation and good ART adherence can drastically reduce this risk of HIV MTCT (Rutstein, 2017). Additionally, based upon MTCT risk factors in research (Rollins et al., 2012), the 2018 Western Cape PMTCT guidelines identify infants at high risk of MTCT, requiring a two-drug post exposure prophylaxis (PEP) regimen (Provincial Government of the Western Cape, 2018). These amended PMTCT guidelines and the South African Guidelines for Early Infant Diagnosis (EID) of HIV resulted in vertical transmission rates decreasing from 4.1% in 2010 to 2.3% in 2012 (Sherman et al., 2017).

By freely providing ART and adherence counselling to HIV positive pregnant mothers and subsequent post-exposure prophylaxis (PEP) to HIV exposed infants, South Africa has sought to ensure that exclusive breastfeeding as an infant feeding option for woman living with HIV, has a low risk of MTCT.

2.5.2 Infant feeding policies

Differences in interpretation and implementation of global infant feeding policies for HIV positive women have occurred between high income countries and middle- and lower-income

countries. For example, American and British health authorities recommend that although an HIV diagnosis does not preclude breastfeeding, formula feeding should generally be advised. Nevertheless, breastfeeding is supported if a mother chooses to rather exclusively breastfeed in these high income countries (British HIV Association, 2019; Mofenson, 2013).

For nearly two decades, South African HCWs have promoted somewhat conflicting messages around infant feeding practices. The South African Infant and Young child feeding (IYCF) policy implemented from 2002 to 2007 discouraged HIV positive mothers from breastfeeding due to the risk of MTCT (Mphasha & Skaal, 2018). Instead, it encouraged exclusive formula feeding (EFF), if a woman qualified in terms of the WHO recommendation of EFF meeting the Affordable, Feasible, Acceptable, Sustainable and Safe (AFASS) criteria (WHO, 2006; Nieuwoudt and Manderson, 2018). Women who chose to EFF were provided with free formula by government clinics (du Plessis et al., 2016). In 2010, based on evidence of EBF's relative safety and its protection afforded to infants from other health problems and EFF not being feasible and unsafe in many resource poor contexts, the WHO recommended that all mothers, regardless of their HIV status, exclusively breastfeed for six months (Vallely et al., 2013). While the 2010 South African PMTCT Guidelines concurred with this recommendation, the guidelines stopped short of recommending EBF as the default feeding option for women living with HIV (Kuhn & Kroon, 2015). However, a year later, in the Tshwane Declaration of 2011, South Africa adopted EBF as the default infant feeding method, including for HIV exposed infants (Office, 2011). The Tshwane Declaration promoted the revision of the IYCF policy in 2013, which recommended six months of EBF for all HIV positive mothers, with continuation of breastfeeding until 12 months. However formula milk could still be provided by HCWs according to specific criteria as outlined in the policy (Mphasha & Skaal, 2018). In addition, it called for ARV therapy to be freely available to all HIV positive mothers to decrease MTCT risk and improve maternal outcomes of all HIV positive mothers (Office, 2011). This shift in policy in 2011 required a shift in the health system and for amended counselling messages to be provided.

A small qualitative study in Soweto conducted with HCWs who experienced the changed policy after the Tshwane Declaration of 2011, reported that the scientific rationale was never explained to HCWs and most believed that the policy had changed for cost related reasons (i.e. that government could no longer afford to supply free formula). Participants were unclear whether they should promote EBF as the only appropriate infant feeding option when counselling all mothers or whether there were other appropriate optimal feeding options, which

may include EFF based upon the individual's risk (Nieuwoudt & Manderson, 2018). This resulted in potentially conflicting and confusing mixed messages around infant feeding for both HIV exposed babies and HIV unexposed babies.

In 2017, amendments were made to the IYCF Policy of 2013 regarding HIV exposed infants (South African National Department of Health, 2017). Continuation of breastfeeding until 24 months of age, followed by gradual weaning of infants, was recommended. Additionally, it recommended that mixed (formula and breast milk) feeding should no longer be an indication to stop breastfeeding. Formula feeding was recommended only in certain circumstances. If an HIV positive mother met the eligibility criteria, then free formula could be prescribed by specific HCWs.

This amendment communicates no further details regarding the infant feeding choice for HIV positive mothers at high risk of MTCT, namely those with high viral load (VL) (>1000 copies/ml) or mothers newly infected with HIV during their third trimester or while breastfeeding. No clear recommendation has been distributed to HCWs with respect to infant feeding guidance for HIV positive mothers at high risk of MTCT, other than the recommendation to refer these patients to medical officers to be assessed for “further management of the mother” and to “assess eligibility of the baby for post exposure prophylaxis (PEP)” (WCDoH, 2017:2). Hence this leaves such advice to medical officers' discretion. Due to the vagueness of these policy amendments, uncertainties about correct infant feeding advice among HCW, may arise. This highlights the need to understand what factors influence maternal infant feeding choice and challenges faced by HCWs when providing infant feeding counselling in the PMTCT setting.

2.6 Factors influencing breastfeeding: A conceptual framework

Factors that influence women to exclusively breastfeed are numerous, and include the potential impact that HCW guidance may have on mothers' infant feeding practices.

Most women are physiologically capable of breastfeeding. Few women are unable to do so due to medical or psychological problems. Rather, individual, historical, cultural and socioeconomic factors that interact with each other have the greatest influence on whether a mother is able to breastfeed or not (Victora et al., 2016). Rollins et al.'s (2016) conceptual framework is useful in outlining which multifaceted factors influence women's ability to successfully practice breastfeeding (Figure 1) as well as in understanding the role of HCWs in promoting EBF for all women, regardless of HIV status.

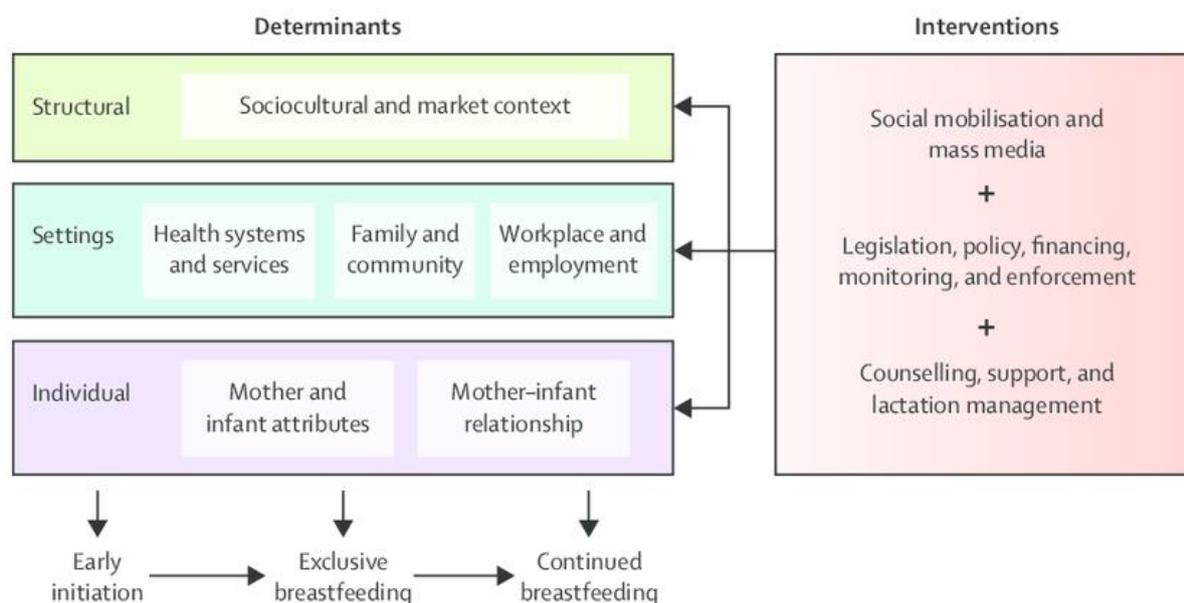


Figure 1: The components of an enabling environment for breastfeeding – a conceptual framework (Rollins et al., 2016).

2.6.1 Structural factors

As illustrated in the above conceptual framework, factors at this level include those which affect the entire population, including existing social trends, the influence of media and advertising as well as the milk substitute products available. Mothers may be influenced in different ways by these structural factors during periods of decision making around infant feeding. While breastfeeding is a natural process, which is best for infants, infant feeding settings may not solely be within mothers' own control. For example, the comfort needed to breastfeed in social settings is likely to impact on mothers being able to carry out their intentions to exclusively breastfeed (Sattari et al., 2010). Women could become daunted by social norms which may dictate that they need to be discrete when they breastfeed. Discomfort with breastfeeding in public has been cited as a contributing factor to breastfeeding cessation (Boyer, 2011).

The influence of social media and commercial marketing of breast milk substitutes on South Africa EBF rates, requires further investigation. Despite the WHO International Code of Marketing of Breast-milk Substitutes (1981), stipulating that there should be no promotion of breast milk substitutes, current marketing strategies of large breast milk substitute companies utilise social media platforms such as Facebook, influencers, bloggers, and YouTube to promote their products. This has created an opportunity for breast milk substitute manufacturers to violate the WHO code through promotional practices that circumvent conventional methods for monitoring and regulating such practices (Abrahams, 2012).

Hence social, cultural and market factors all contribute to the structural context of breastfeeding. They impact on a woman's decision and practical ability to exclusively breastfeed and on its duration. HCWs are uniquely positioned to counter or confirm such information, provided they themselves have up to date knowledge.

2.6.2 Influences of the contexts in which infant feeding occurs

As highlighted in the conceptual framework, social and family pressures may affect mothers' infant feeding practices. Within families and communities, previous and current infant feeding practices and experiences may influence what infant feeding method a mother will adopt (Rollins et al., 2016). For example, some cultures regard colostrum as harmful to a baby and a family member may therefore urge a mother to discard a little milk before each breastfeed (Sibeko et al., 2005). The baby's father's attitudes and preferences toward different infant feeding methods may also have a strong bearing on a woman's breastfeeding practices (Rempel & Rempel, 2011).

Women's economic circumstances further influence the infant feeding options available to them. Returning to work is frequently reported as a reason for cessation of breastfeeding (Schubl, Goosen & McLachlan, 2014). The rising proportion of women joining the workforce is a major factor in breastfeeding discontinuation. Despite improved understanding and knowledge about the benefits of exclusive breastfeeding among women, fewer employed women are able to practice the recommended six months exclusive breastfeeding compared to unemployed women (Nigatu & Worku, 2014). A systematic review found that providing physical facilities to breastfeed (private location, breast pumps and breast milk storage facilities), was essential to the promotion of breastfeeding in the workplace. Implementing breastfeeding friendly employment policies (job-flexibility and nursing breaks) provides mothers with the freedom to express breast milk. But the most important factor is to ensure working mothers are aware of the benefits of breastfeeding as well as the existence of workplace policies, which allow women to breastfeed while at work and not feel judged by colleagues and managers when utilising these opportunities (Hirani & Karmaliani, 2013). Paid maternity leave has been cited as a strategy to increase exclusive breastfeeding practices among working mothers. However, South Africa offers no maternity benefits to mothers working in the informal sector and although permanently employed woman are entitled to four months of maternity leave, very few enjoy paid maternity leave commensurate with their regular earnings during this period. This can result in suboptimal feeding practices, as working mothers return

to work early to resume their full income (Du Plessis et al., 2016). A Western Cape study found that mothers prefer to leave formula milk rather than their expressed breastmilk with caregivers while they are at work (Goosen, 2014). They believe it is more convenient for the carer to provide formula milk in a bottle to the infant as this leads to the infant crying less. The decision of a working mother to stop breastfeeding is multidimensional, but may include fatigue, practicality, intensity, workplace policy and colleagues' acceptance (Roe et al., 1999).

Within the health system, HCWs are present at key moments, antenatally and postnatally, when mothers make decisions about infant feeding practices. Although HCWs are not able to influence family members or employers of a breastfeeding mother – they can assist her to anticipate and navigate the potential challenges at home and work. Gaps in HCW training and knowledge of infant feeding, can contribute to HCWs providing insufficient advice and potentially contradictory messages, to mothers (Adeniyi et al., 2019).

2.6.3 Individual influencing factors

Individual factor as identified in the conceptual framework relate directly to the mother and infant pair. They include her intention to breastfeed, her knowledge, previous experiences with infant feeding and her own health. Prenatal intention to breastfeed is among the strongest predictors of breastfeeding. Maternal knowledge, subjective norms and beliefs contribute to the intention and duration of breastfeeding (Sattari et al., 2010). Maternal confidence and intention to breastfeed can be undermined by family advice, HCW attitudes, and cultural norms. HCWs are pivotal role players of infant feeding messages, and mothers often make decisions based primarily on this advice, despite other external pressures (Fjeld et al., 2008; Horwood, Jama, et al., 2019). Inadequate HCW support and advice in the event of poor infant latching, painful nipples and a mother's exhaustion, can result in a mother abandoning breastfeeding (Brown *et al.*, 2014). Insufficient milk supply resulting in infant fussiness and inability to settle the child are common reasons cited for women's cessation of exclusive breastfeeding. Maternal health including obesity, depression, and post-delivery recovery also contribute to the feasibility of exclusive breastfeeding for women (Rollins et al., 2016).

2.6.4 HCWs as a determinant of infant feeding choice

A HCW remains one of the greatest influencers on infant feeding decisions, both antenatally and postnatally (Nigel C Rollins et al., 2016). Multiple factors underpin the advice which HCWs provide on infant feeding during counselling.

HCW views and personal beliefs influence EBF: HCW personal views and beliefs are identified as key factors influencing HCW counselling. Although HCWs may have knowledge regarding breastfeeding's overall advantages for mother and infant, their views regarding the actual feasibility of practising EBF may outweigh this knowledge in the counselling they provide (Tuthill, Chan & Butler, 2015). In addition, HCWs may provide counselling based upon their own experiences and individual beliefs, which do not always align with official guidelines. For HCWs working in settings in which they advise HIV positive mothers, this can act as a barrier to recommending EBF. If they do not believe in the merits of changed infant feeding guidelines, they may not feel comfortable conveying the official new infant feeding recommendations to patients (Piwoz et al., 2006). Some studies have found that HCWs may elect not to introduce all available feeding options to mothers living with HIV due to their own fear and misinformation on the MTCT risk (Seidel, 2000; Koricho, Moland and Blystad, 2010). Conversely, the views of other HCWs may lead them to be prescriptive in their infant feeding counselling, insisting that breastfeeding is the only infant feeding option that a mother should follow. Maternal choice, patient HIV status and VL level may be insufficiently considered under these circumstances (Seidel, 2000).

HCW confusion surrounding changes in infant feeding recommendations can translate into mistrust because of the varying and sometimes confusing messages they appear to provide (Tuthill, McGrath & Young, 2014). Contradictory or confusing messages provided at different stages of antenatal and postnatal care and in different healthcare service settings can result in mothers feeling overwhelmed and confused by the information they receive (Tuthill, Chan & Butler, 2015). In one qualitative study conducted in Tanzania, none of the counsellors interviewed had practiced EBF themselves. They therefore lacked breastfeeding experiences and additionally all reported that they would not breastfeed if they were diagnosed as being HIV positive (De Paoli, Manongi & Klepp, 2002).

HCW workload as an infant feeding counselling challenge: Ideally, patient centred counselling is meant to be practiced. However due to HCW workload pressures, infant feeding counselling often becomes a one-way and prescriptive session in which health information is simply relayed by the HCW, without opportunities for discussion (Leshabari, Blystad & Moland, 2007). In addition, HCWs face challenges, with having few practical strategies to equip mothers who are facing barriers to EBF. Limited time with patients hinders the HCWs ability to explore each mother's context and social norms that influence her ability to exclusively breastfeed. Time constraints also hinder the development of individualized strategies to

manage the logistics of the mother returning to work. This may result in HCWs feeling that they are insufficiently able to support patients. (Tuthill, Chan & Butler, 2015).

HCWs as role players in MTCT elimination: Van de Perre et al. (2017) highlight that the current strategies to eliminate MTCT, including regular HIV testing of HIV negative mothers, same day ART initiation of HIV positive pregnant and breastfeeding women and regular VL monitoring of HIV positive mothers during pregnancy and breastfeeding, are insufficient. They suggested that although ensuring maternal ART should remain a priority, interventions to improve regular sustained engagement with HIV care (retention in care) and Pre-exposure prophylaxis (PrEP) for infants exposed to HIV via breastfeeding, should also be prioritised. The Western Cape amended 2013 IYCF policy no longer allows for distribution of free formula if a woman wishes to adopt exclusive formula feeding rather than EBF. Instead, it only allows free provision of replacement feeds, for mothers failing the second line of third line treatment and mothers who are too ill to breastfeed (Provincial Western Cape Department of Health, 2017). Limited literature is available regarding HCWs feelings and opinions on being unable to provide alternative infant feeding strategies to mothers at high risk of MTCT.

HCWs perceived practical barriers to EBF: One study by Piwoz et al., (2006) found that some HCWs believe that women practicing EBF for six months was unrealistic. They cited cultural norms in a number of different contexts that encourage introducing solids to infants at three to four months of age. Another study found some HCWs believe returning to work causes many mothers to formula feed (Tuthill, Chan & Butler, 2015).

2.6.5 Policy translation as a determinant of infant feeding choice

The HCWs ability to retain some degree of freedom or discretion to decide what should be done in certain circumstances is well recognized as an important component of policy implementation (Barnes and Henly, 2018; Thomann, van Engen and Tummers, 2018). Often referred to as ‘street level-bureaucrats’, these frontline HCWs have the potential to strengthen the health system with their flexibility and resilience to adapt to changing demands, especially in resource limited settings. However, HCW discretion can potentially jeopardize optimal patient care, when a HCW deviates from policy (Nunes and Lotta, 2019). The question as to whether and if so, in what circumstances HCWs should be allowed some degree of discretion in policy implementation, is beyond the scope of this mini thesis. However, it remains an ongoing debate (Thomann, van Engen and Tummers, 2018). The impact of HWC discretion is illustrated below (Figure 2) in Tummers & Bekker’s (2014) framework which depicts the

impact HCW discretion has, firstly on the added meaning the policy will have for patient care and secondly, on the HCWs willingness to implement the policy.

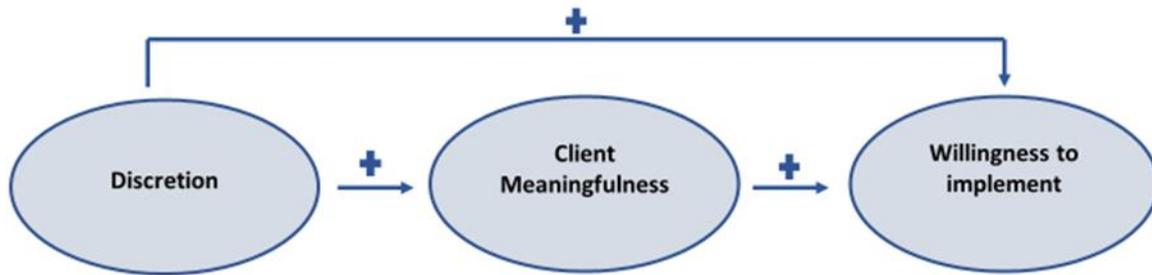


Figure 2: Proposed theoretical framework regarding two main effects of discretion (Tummers and Bekkers, 2014)

HCW discretion influences how meaningful the policy is to a patient, and therefore allows the HCW to tailor their decisions and actions to suit the needs of the specific patient. (Tummers and Bekkers, 2014). This allows frontline HCWs to use their own clinical judgement when managing the desires, expectations and needs of patients.

It is important for policy makers to understand how HCWs interpret and experience infant feeding guidelines, due to their pivotal role in the infant feeding decision. In order for HCWs to develop a positive attitude towards a policy and its implementation, they need to perceive it as meaningful for the community and patient (Tummers, 2012). HCW confusion surrounding MTCT risk and EBF feasibility (Piwoz et al., 2006; Janse van Rensburg, Nel and Walsh, 2016) may influence HCWs perceptions of the infant feeding policy. Additionally, vagueness in policy may lead to its implementation being subject to the interpretive discretion of HCWs (Bergen and While, 2005). HCWs therefore can either help mothers, including mothers at high risk of MTCT, to choose from an array of infant feeding strategies, or they could strictly counsel on only one feeding option. While research has identified HCW knowledge regarding infant feeding as a challenge to previous guideline implementation (Piwoz et al., 2006; Valley et al., 2013; Janse van Rensburg, Nel and Walsh, 2016), little is known about how HCWs have responded specifically to the amended South African IYCF policy and PMTCT policy, especially in the case of mothers at high risk of MTCT.

2.7 Understanding postnatal Mother to child transmission

The transmission of HIV from a mother to her child can occur before, during or after delivery and is referred to as vertical or Mother to Child transmission (MTCT). HCWs understanding of when and how HIV MTCT occurs, is likely to influence the infant feeding guidance they provide to HIV positive mothers (Jama et al., 2017). The following section reviews the literature on different factors associated with HIV MTCT.

2.7.1 HIV in Breast Milk

The factors associated with MTCT through breast milk are multifaceted and poorly understood. Several mechanisms have been proposed, however most MTCT events are thought to be due to the exposure of the infant's mucosal gastrointestinal and nasopharyngeal surfaces to HIV (Van de Perre, 2012). Nevertheless, the risk of MTCT through this transmission route is minimal, with less than 1% of exposed infants infected during breastfeeding (Kuhn & Kroon, 2015).

The two main factors associated with MTCT during breastfeeding are the maternal plasma VL and breast milk VL (Newell, 2003; Church, 2004; Kourtis and Bulterys, 2012). Mixed feeding is another MTCT risk factor and has found to increase the risk of MTCT by two-fold (Coutsoudis et al., 2001; Coovadia et al., 2007).

Provision of maternal ART decreases the risk of MTCT by 10-fold during the postnatal period (Kuhn & Kroon, 2015). However, adherence to ART, so that the maternal viral load is low, is a key factor in minimising HIV transmission. Myer et al., (2017b) found an 8.5% MTCT risk when the maternal VL was > 1000 copies/mL at delivery (i.e the viral load was high and therefore unsuppressed). In contrast, the likelihood of HIV transmission to another person, including an infant, is minimal, if not completely negligible, from an HIV positive patient who is adherent to ART, with suppressed viral RNA replication (i.e. the patient's viral load is virtually undetectable) (LeMessurier et al., 2018). Approximately 81% of postpartum transmissions occur in the first six months of the infant's life (Goga et al., 2016), making this a most critical period in preventing HIV MTCT through infant feeding. Ensuring maternal VL suppression, is therefore of utmost importance in a PMTCT program. Nevertheless, although MTCT risk correlates with high maternal VL, occasionally transmission risk can occur at very low or even undetectable viral load levels (Newell, 2003).

2.7.2 HCWs perception of MTCT and breastfeeding

Since the 2011 Tshwane Declaration, EBF rates have increased in the country (Statistics South Africa, 2017), however maintaining EBF practice is perceived as a challenge by many HCWs, due to external factors, including family and employment pressure (Al-Mujtaba, Sam-Agudu and Khatri, 2016).

Some studies suggest that HCWs may have fair knowledge of the recommended infant feeding options (Janse van Rensburg, Nel and Walsh, 2016; Iliyasu et al., 2019). However they feel undermined by the limited infant feeding choices they can offer to mothers (Desclaux and Alfieri, 2009; Nieuwoudt and Manderson, 2018). Therefore, some HCWs may adapt their counselling according to what they believe to be the best infant feeding option for a mother (Tijou Traoré et al., 2009; Wachira et al., 2009; Madiba and Letsoalo, 2013). For example, HCWs may promote exclusive formula feeding among mothers they perceive to have a high socioeconomic status, believing that they have the finances, equipment and clean water to provide formula safely. (Koricho, Moland and Blystad, 2010; Chinkonde, Hem and Sundby, 2012). Additionally, other studies have found HCWs to be concerned about EBF feasibility in women they perceive as undernourished (Buskens, Jaffe and Mkhathshwa, 2007; Leshabari et al., 2007).

The majority of women are likely to choose EBF because it is a culturally accepted norm of infant feeding and bonding (Buskens, Jaffe and Mkhathshwa, 2007; Hofmann et al., 2009). However practical constraints can make adhering to EBF challenging for many women (Chinkonde, Hem & Sundby, 2012; Musa, 2012). Despite the many benefits of breastfeeding as perceived by HCWs, some studies have found that they view women adopting EBF for the first six months as impractical and unfeasible for certain women, such as those returning to work (Leshabari et al., 2007; Fadnes et al., 2010). Moreover unplanned pregnancy, unpaid or low paid maternity leave, food insecurity and HIV, are factors perceived as potential barriers to EBF by some HCWs (Goosen, McLachlan and Schübl, 2014). Mixed feeding, therefore, is most often the infant feeding practice adopted eventually by most women (Leshabari et al., 2007; Fadnes et al., 2010). One study found that HCWs perceived the removal of free formula as a contributing factor to the high mixed feeding rates (Saloojee, Gray and McIntyre, 2011).

Fear of HIV transmission during breastfeeding influences the infant feeding choice (De Paoli, Manongi and Klepp, 2002; Hofmann et al., 2009; Koricho, Moland and Blystad, 2010). However the literature suggests that HCWs may overemphasise this risk to mothers, creating

unwarranted concern and influence mothers to choose formula feeding over EBF (Koricho, Moland and Blystad, 2010; Kafulafula et al., 2014; Nieuwoudt and Manderson, 2018). Despite available literature regarding MTCT risk factors, limited literature is available regarding HCWs perception of this risk and what they therefore subsequently communicate about the risk to mothers. For example, Haffejee, Ports and Mosavel (2016) found that only 25% of HCWs in a Durban study, were aware that MTCT could occur through breastfeeding. Studies suggest that some HCWs may perceive EBF mainly as a MTCT preventative strategy, rather than an optimal nutritional strategy. Therefore, they do not promote and counsel HIV negative mothers on the benefits of EBF as emphatically as they do an HIV positive mother (Mnyani et al., 2017; Nieuwoudt and Manderson, 2018). Due to the small risk of MTCT which exists for even VL suppressed mothers, contradictory and controversial infant feeding guidance for HIV positive mothers can occur. Additionally the conundrum of mothers with poor ART adherence, unsuppressed VL and HCWs perceived risk of MTCT, may result in clinicians being unsure of the best infant feeding choice guidance for mothers (Horwood, Jama, et al., 2019).

Chapter Three: Methodology

This chapter describes how the study's aims and objectives were achieved. It provides details of the study setting, the research design, the study population, sampling techniques and the processes involved in data collection, management, and analyses. It further explains the procedures for ensuring rigour and addressing research ethical considerations.

3.1 Research design and methods

The research design was exploratory and descriptive, in accordance with the research problem. Qualitative methodology was used to meet the aim and objectives of the study and to gain a holistic understanding of the subject being studied (Roller and Long, 2001). Qualitative studies aim to gain in-depth understanding by exploring the meaning people give to their context, and how their situation affects their decisions (Robson, 2011). This is achieved by learning about the research participants' 'social and material experiences, perspectives and histories' (Richie & Lewis, 2003:16). Accordingly, this methodology was chosen as the appropriate choice for a study exploring the experiences and perceptions of HCWs regarding the Infant and Young Child feeding policy and their subsequent decisions and actions regarding infant feeding options which they provide to HIV positive mothers.

A flexible approach utilised in qualitative research permits researchers to ask open ended questions, such as "why", "what" and "how" in order to understand a phenomenon (Lacey and Luff, 2007). Therefore this open-ended, inductive approach was utilised to discover meanings and influences on the phenomenon being studied.

A qualitative approach to design and methods has several advantages. It allows for questions to be modified as new data is collected (Draper, 2017). It accepts that although a reality and truth does exist, the study can only understand it imperfectly; in part, due to the researcher's limitations (Robson, 2011). Qualitative research can embrace interpretivist values, which emphasise that a research participant's understanding arises from both experience and reflecting and thinking about what happens to oneself (Ritchie & Lewis, 2003).

In addition, qualitative research methods promote a holistic focus on both individual, medical and behavioural influences, as well as broader social, political and economic influences (Baum, 1995). Qualitative research is not only concerned with the behaviour occurring (such as the HCW advice being provided), but also with the study participants' understanding of what

influences their behaviour (Maxwell, 2012). Qualitative research is well-suited to exploring people's opinions, behaviours, values, and social contexts and providing in depth descriptions of how people experience a given issue (Mack, 2005). Additionally, it can illuminate how previous experiences influence human decisions and actions regarding infant feeding advice. Qualitative research, although not unconcerned about outcomes, is focused on the processes and steps that lead to the outcomes (Khankeh et al., 2015). By using a qualitative approach, this study sought to contribute to the understanding of HCW experiences, perceptions and guidance given regarding infant feeding among HIV positive mothers. Based on this increased understanding of HCWs, recommendations to strengthen the implementation of the infant feeding policy, can be made.

3.2 Study setting

The study setting was three public primary care facilities in Khayelitsha. Khayelitsha is a peri-urban suburb located in the eastern part of Cape Town. Nearly 10% of the Cape Town metropolitan population live in Khayelitsha, making it the largest township in the Western Cape. Neighbourhoods within Khayelitsha contain both formal (access to inside water and electricity), and informal settlements (communal water points and sanitation) (Stats SA, 2011). Poverty is rife, with unemployment estimated to be 41.7% in formal settlements and 54.5% for those living in informal structures (Smit et al., 2016). It has the highest HIV prevalence in the Western Cape, with approximately 34.3% of antenatal women testing HIV-positive in 2012 compared to 29.5% nationally. It has one of the largest and longest ART programmes in South Africa, with approximately 47 000 patients on ART in 2018 (Stinson et al., 2017).

The Khayelitsha population is mobile, with a high rate of circular migration of people between this urban centre and the rural areas of the Eastern Cape Province, where many have family ties. The high rates of poverty, violence and mental health issues make this population vulnerable in terms of access to and engagement with health services (Stinson et al., 2017).

3.3 Study Population and sampling process

Study population: The study population consisted of ten HCWs who provide services to HIV positive females in three Khayelitsha clinics and two HCWs who coordinate the PMTCT programme at subdistrict level. Different cadres of staff were included in the study population including professional nurses, clinical nurse practitioners and doctors appointed as medical officers.

Sampling Process: A purposive sampling method was used to recruit participants. Purposive sampling is most suitable for qualitative research as it allows the researcher to include individuals who have valuable knowledge and relevant experience of the phenomenon researched (Etikan, 2016). Using this sampling method in this research allowed the most suitable participants to be selected based on their knowledge and experience in providing clinical care to breastfeeding HIV positive women. Maximum variation sampling was used to capture a variety of perspectives from HCWs with diverse qualifications and roles in providing healthcare and counselling to pregnant women

Inclusion criteria:

Healthcare workers were selected for an interview, based upon the following criteria:

- a) The HCW had been working in a clinic offering basic antenatal care (BANC) for at least one year prior to the interview or as a district coordinator for a relevant related programme.
- b) The HCW had been working in the Western Cape Province for at least one year prior to the interview.

The amended Infant and Young Child Feeding (IYCF) policy is specific to the Western Cape Province. Therefore, a participant working in the Western Cape for longer than one year was likely to be familiar with the policy. Additionally, a HCW providing BANC services for longer than one year, was more likely to have provided care to virologically unsuppressed HIV-positive mothers.

Identification and selection of HCWs occurred with the assistance of the facility's management who suggested names of HCWs who met these criteria.

Sample size: A total of twelve HCWs were recruited for participation in the study: four medical officers, six nurses and two nurses working as program coordinators at sub district level. Participants were interviewed with the aim of continuing interviews until data saturation was reached (Saunders et al., 2018).

3.4 Data collection and management

Data collection: The researcher was trained in qualitative research methods. Data collection took place between August and October 2019; all data was collected by the researcher in English. English was selected as the chosen medium by participants, who indicated that they

were comfortable being interviewed in English and all declined the offer of an isiXhosa research assistant to conduct the interview.

Once the study's aim and purpose were presented to the different facility management teams, management assisted in identifying potential participants who met the inclusion criteria. Identified potential HCW participants were approached for participant possible recruitment into the study. In addition, two coordinator nurse participants were recruited from the Khayelitsha substructure office, both of whom are involved in coordinating relevant programs at the Metro Health Service (MHS) facilities in Khayelitsha.

After informing each potential HCW participant about the purpose of the study, the participant was provided with a Participant Information Form (Appendix 1). After the participant consented to study participation, the researcher and participant agreed upon a date and time to conduct an in-depth interview.

At the agreed upon date and time, the researcher met the participant in their private consultation room at the facility where they work. A semi-structure interview guide (Appendix 3) was utilised to guide the in-depth interview (IDI) with each participant. The use of a semi-structure interview guide was selected due to the flexibility offered by the tool, which included prompts to further explore emerging issues with participants (Mann, 2016). In-depth interviews were selected rather than focus groups discussions (FGD), as FDG would require several HCW to be released from their work duties simultaneous, thereby interrupting health services on the day of the FGD. The interview guide included preliminary questions to document participants' educational and work background. The remainder of the questions explored their familiarity with the previous and current infant feeding policies and their perceptions and feelings regarding optimal infant feeding practices for HIV positive mothers. Participants were also asked to discuss their role and experience in counselling HIV positive mothers regarding infant feeding options.

The face-to-face IDIs were conducted by the researcher in English and audio recorded with consent from the participant, for subsequent transcription. In addition, field notes were kept for later corroboration and data analyses. After 12 IDIs were completed, data saturation was achieved, with no new insights emerging.

Data management: The interviews conducted by the researcher were audio-recorded and transcribed verbatim by the researcher. Participants were assigned study codes and all personal identifying information was removed from the transcripts. The transcripts were saved in plain text in MS Word. After transcription thematic coding, analysis was applied to the transcripts.

3.5 Data analyses

Thematic analysis was used to identify and interpret patterns which emerged from this study. The systematic six phase process for qualitative thematic data analysis as described by Clark and Braun (2014), was followed ; i) familiarization, ii) develop initial codes, iii) identify potential themes, iv) review potential themes, v) define and name themes and vi) produce the report.

Data set familiarization: The analysis process began with careful listening to the audio recorded IDIs and comparing and consolidating impressions with the field notes taken during data collection. This allowed the researcher to immerse herself in the data, so as to gain a comprehensive overview of the data collected. Transcription of the recorded IDIs was then conducted verbatim, which contributed to the continued immersion of the researcher in the data. During the familiarization process, the initial identification and documentation of relevant features to the research question, occurred.

Coding: Thematic coding analysis is a ‘method for identifying, analysing, organizing, describing, and reporting themes found within a data set’ (Nowell et al., 2017:2). Data analysis was done manually with systematic open coding to generate initial codes. Each transcript line was read and re-read to ensure appropriate codes were applied. These initial codes were labels which identified points of interest about the data. Additionally, written notes were kept in columns, documenting ideas and thoughts.

Identifying themes: Once all the transcripts were coded, the common concepts, perceptions and behaviours were summarised for construction of the preliminary analysis. Theme development occurred by examining the broader patterns of the initial codes and clustering them together. Initial categories were used to organise the data into manageable and relevant segments. After the initial categories were processed, Microsoft Excel sheets were used to manage the different categories and subcategories. Text extracts were used to illustrate the emerging themes. The manual thematic coding analysis process resulted in developing a MS

Excel data sheet from which further interpretation could occur. Through this process of coding and categorising the identified themes, the researcher was able to confer meaning to the participants' responses (Ritchie & Lewis, 2003). Additionally, the researcher's supervisor provided guidance during the analysis process and confirmed the findings.

Reviewing themes: Once themes were identified, further clustering of overlapping and related themes and possible linkages between themes, were identified. Several working theme names were assigned to the identified themes, as well as the identified sub themes. The themes were reviewed by both the researcher and the researcher's supervisor to ensure that they captured the coded features and were coherent and relevant to the research question.

Defining and naming: The final theme names were decided upon. Interpretation of the themes drew on theory and prior research to provide explanations for the findings. Text extracts from the data were chosen to illustrate the analytic points that the researcher wished to convey to the reader.

3.6 Rigour and trustworthiness

Trustworthiness is essential to qualitative research to ensure that the research findings are reliable and dependable (Ritchie, 2012). Therefore, throughout the entire study, Lincoln and Guba's (1986) criteria of credibility, dependability, confirmability, and transferability were adhered to, to ensure rigour.

Credibility: Several strategies were employed by the researcher to enhance credibility. This included initial immersion in literature to expand the researcher's understanding of the phenomena being studied as described above. The researcher summarised key points after each interview to ensure that the perceptions, experiences and opinions of the participants were accurately captured. Additionally, working in Khayelitsha during the previous year allowed the researcher to gain greater insight into the HCW-patient relationships as well as into the different facilities' working cultures. Triangulation of data sources increased the study's rigour. The study involved different cadres of staff being interviewed, allowing the researcher to interrogate the data gleaned. This contributed to the study's rigour as it pulled together data from different, independent vantage points, thus minimizing bias from a single source (Shenton, 2004).

Dependability: In this study, the data collection process and data analysis are described in detail, thereby contributing to the dependability of the study. Dependability is concerned with keeping careful track of the emerging research design and research activities, and should be as explicit and as repeatable as possible (Morrow, 2005).

Transferability: A ‘thick’ description has been provided regarding the context of the study area, the selection of the participants, and the procedure for data collection and analysis. This allows for other researchers to consider the possibility of transferring the findings related to similar issues and explore these within their own context (Nowell et al., 2017).

Confirmability: By striving to ensure credibility, dependability and transferability, the researcher has ensured, as far as possible, representation of the perceptions and attitudes of the participants, and not her own.

Reflexivity: Researcher reflexivity involved the researcher reflecting on her background, personal beliefs, values, and biases and how they may influence the study. A research diary was kept regarding personal thoughts, beliefs and feelings, throughout the study period for personal monitoring (Wong, 2008). Malterud (2001) refers to a process in which qualitative researchers acknowledge that their background, context and experience can influence the way in which they choose to conduct research. These preconceptions may impact the analysis and communication of the study findings. Therefore, to conclude the review of trustworthiness, a brief description of the researcher is essential to consider the effect of the researcher’s role on the study outcomes. This section is written in the first person.

Background and social position:

As a medical doctor and mother, I have my own personal beliefs regarding the Infant and Young Child Infant feeding policy, especially in relation to mothers with high viral loads. Therefore, this interest did influence the choice of topic and the qualitative method chosen to conduct the research. As a doctor overseeing a program, I was motivated to understand the gap between what the policy says and what is being done.

My role and position within the Department of Health may have influenced certain aspects of the research process in several ways. Firstly, my position as a medical doctor may be viewed by other healthcare workers as being perhaps ‘higher’ in the traditional hierarchical system. I believe that my study presentation to the facility managers, my interactions with the healthcare workers and my reputation amongst them, allowed me to gain access to the healthcare workers easily, but that they nevertheless did not feel compelled to participate in the study. Secondly,

being the interviewer, I was concerned that participants may not be open in expressing their actual practices and the advice they gave to patients. However, throughout the interviews, in order to create an atmosphere of trust and transparency, I encouraged the participants to view me as wearing a researcher ‘hat’ and that there were no right or wrong practices. I also emphasised that I was a student and I was learning from them, as I had done in learning the skills of qualitative research. Lastly, I have recently become a mother and have now experienced many of the ‘excuses’ for not breastfeeding that patients give to healthcare workers – like ‘just not enough milk’, and ‘returning to work’ or ‘cracked and bleeding nipples’. Therefore, I am both a healthcare worker who advocates breastfeeding, and a mother who often cried over the pressure to breastfeed, the pain experienced while breastfeeding and a child with poor weight gain. I can relate to both role-players, and subsequently my attitude and preconceived beliefs regarding breastfeeding, have changed.

3.7 Ethical considerations

Due to the nature of this study, human participants were involved and therefore the design, proposal and conduct of the study was guided by the ethical principles of autonomy, non-maleficence, beneficence, and justice. Key steps were taken to ensure that participants were informed, , guaranteed confidentiality, not harmed and that they provided consent (Mann, 2016).

Ethical clearance for the study was received from the UWC Higher Degrees Committee and the UWC Biomedical Ethics Research Committee (BMREC) at the University of Western Cape (reference number BM 19/1/3). Ethical clearance was obtained before data collection occurred and was valid for the period February 2019 to February 2020 (Appendix 4). In addition, permission to conduct the study was sought and obtained from the Western Cape Department of Health (WCDoH), the Khayelitsha Eastern sub-structure (KESS) and the management and staff at the Khayelitsha health facilities where the participants work.

The ‘cornerstone of ethical conduct’ is to avoid harm (Lichtman, 2012:52). The researcher explained in private the purpose of the research and the nature of data collection to each potential participant. The potential risk which can occur whenever a person discusses their personal beliefs or actions was acknowledged, however it was explained that all measures

would be taken to ensure that if any emotional distress occurred, then appropriate referral to a relevant health professional, would be sought.

The purpose of the research and the confidential nature of the study was explained to participants in English, as all participants were fluent in English. Each participant was informed that their decision to participate was completely voluntary and that they had the right not to participate or, if they agreed to participate, to withdraw their consent at any point during the study. It was clarified for every participant that there would be no consequences should they decide to withdraw or decide not to participate in the study. Potential ethical issues were anticipated during the research proposal preparation, thus informed consent was obtained and steps were taken to ensure confidentiality during data collection, analyses and reporting (Orb, Eisenhauer and Wynaden, 2000). The interviewer explained that the participant could decline to answer any of the questions and that there were no incorrect or correct answers. Lastly, the participants were informed and gave consent to an audio recording of the interview. Once verbal consent was obtained from the participants, they were asked to sign the informed consent form (Appendix 2).

No reimbursement was offered to the participants for their participation in the study. However, the benefit from participating in the study was explained during recruitment, namely that the research findings could contribute to an improved understanding of the challenges faced by HCWs when providing infant feeding counselling to HIV positive mothers.

Each participant was given a unique study numerical identifier, rather than names being used. All names and references to other HCWs or the facilities, were removed from the transcripts. The transcribed data and the coding sheets with respondent numbers (identifiers) were stored in files on a password locked computer, to which only the researcher had access. No individual statements were linked to specific participants or presented in such a way so as to potentially reveal the identity of a respondent. The consent forms were stored separately from the transcribed interviews in a locked cabinet in a secured office. All audio and test data will be destroyed after five years.

Chapter Four: Findings

4.1 Introduction

This chapter presents the findings from the study's in-depth interviews (IDIs) with HCW participants. The chapter begins by providing an overview of the participants' demographic and work characteristics. The findings from the analysis of the IDIs are organised into central themes guided by the study's aim and objectives. Each theme is subsequently divided into further sub-themes. The central themes and sub-themes are elaborated on below. Quotations from the IDIs, used to illustrate the findings, have been labelled with a study participant number and job category within the health services. This is in order to maintain confidentiality

4.2 Participant background characteristics

Table 1 below provides the background demographic and work characteristics of the participants. All 12 participants were HCWs working in the Khayelitsha health sub-district in the Cape Metro and were involved in HIV related health service provision for HIV positive women or worked as sub-district coordinators in related programmes. Participants were selected from a spread of job categories including professional nurses (PNs), clinical nurse practitioners (CNPs), doctors and programme coordinators. Most had more than five years of experience in HIV care and worked in General ART services. Ten out of the 12 participants had only ever worked within the Western Cape provincial health sector. Most had more than five years of experience in HIV care and worked in various departments in the health facilities as listed below.

Table 1: Participant background characteristics

Participant characteristics		Number
Staff cadre categories	PN	2
	CNP	4
	Doctor	4
	Programme coordinator	2
Clinical years of work in HIV program	< 5 years	1
	5 – 10 years	4
	>10 years	7
Current work department	MOU/BANC	3
	Paediatric services	1
	General ART	6

	Substructure office	2
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4.3 In depth interview findings

The findings from the in depth interview analysis are clustered into five central themes, reflecting the key factors that emerged in accordance with the aim and objectives of the study. These include: HCW awareness, familiarity and understanding of the new infant feeding policy; Processes of new policy implementation; HCW views on women’s ability to implement infant feeding choices and new policy acceptance; HCW infant feeding messaging and counselling (Infant feeding messages and counselling provided to patients by HCWs); and HCW recommendations for messages, counselling and service provision. Further sub-themes were identified within each theme and are presented in Table 2 below.

Table 2: Themes and sub-themes

Theme	Sub-theme
HCW awareness, familiarity and understanding of the new infant feeding policy	Vague non-specific knowledge of new infant feeding policy
	Policy dissemination shortcomings
	Diverse views on advantages and disadvantages of new policy
	Perceptions of reasons for infant feeding policy changes
Processes of new policy implementation	Transition vs. immediate policy implementation
	Uneven CHW training on new policy
	A gradual ‘pathway’ to acceptance of policy changes for patients
	HCW policy acceptance when theoretically applied to own lives
Women’s ability to implement safer infant feeding choices	Personal and interpersonal maternal factors
	Maternal socio-cultural and economic factors
	Health service factors
HCW infant feeding messaging and counselling	Content of counselling message
	Importance of patient centred approach, continuity of care and individualized counselling
	Responsibility for infant feeding counselling
	The HCW as a factor influencing safe infant feeding practices
	Patient centred infant feeding counselling challenges
HCW recommendations	HCW recommendations for messages and counselling
	HCW recommendations for greater flexibility in decision making

4.3.1. HCW awareness, familiarity and understanding of the infant feeding policy

4.3.1.1. Vague non-specific knowledge of new infant feeding policy

All participants were aware that the infant feeding policy had changed in the recent past, although some were uncertain exactly when the policy changes were introduced. They reported that they were clear that previous policy allowed HCWs to provide free formula to HIV positive mothers and that mothers therefore had had a choice of electing either to breastfeed or formula feed. As one participant stated:

Yes, with that [the previous] infant [feeding] policy what they covered was that any exposed mother would have a choice, [if] we would prefer and [we would tell] the mother basically we think you should rather formula feed and then we would ensure that we provide the [formula] feeds to the mother on a monthly basis and then ask them not to breastfeed. (P03,CNP)

In contrast, although participants were aware that the new Department of Health (DoH) infant feeding policy encouraged HCWs to now only promote exclusive breastfeeding, regardless of a woman's HIV status, most participants were vague about the specific circumstances in which a health facility would still be allowed to provide free formula feed to a woman. Some offered the view that a health facility would be allowed to provide free formula feed in the case of a grandmother being the infant's primary caregiver or in the case of an adopted baby. A few were aware that formula could still be provided to HIV positive mothers if they met certain medical criteria. These included maternal hospitalization or if a woman was failing second line ART. However the procedures to obtain appropriate permission for this were viewed as arduous. This is reflected in the view expressed by one participant:

We did have a woman with a high viral load who delivered a negative baby and the paediatric sister managed to get free formula! Ah, I don't know how he did it. (P11, Doctor)

In addition, several participants felt they lacked guidance on specific aspects of the infant feeding policy. This included what advice they should provide to HIV positive mothers on mixed feeding and the duration of breastfeeding. Some HCW stated that they found it difficult to keep up with and implement changes that occurred in the PMTCT infant feeding policy. As one participant stated:

I have not, to be honest with you, I have not kept myself abreast with changes in PMTCT guidelines because it is just very confusing and all, you know. (P12, Doctor)

4.3.1.2. Policy dissemination shortcomings

Poor dissemination of the policy changes was cited as a key reason for HCWs not being sufficiently clear on the details of the changed infant feeding policy.

I know there is a [changed] breastfeeding policy but it hasn't disseminated down to everybody so [that] we can all have the same voice, ja. (P10, Doctor)

Dieticians were identified as being responsible for managing patients' access to free formula feed by most of the participants, however a few participants were unaware of the process to be followed to access free formula feed for a mother. The procedure to acquire free formula feed as described by participants who were aware of the process, was for HCWs to refer a HIV-positive mother to a dietician to be assessed as to whether she met the criteria to receive formula feed:

We refer to the dietician, so the dietician is going to see if they have some milk... (P04_PN)

This procedure differed from the previous guideline's procedures, in which participants reported that a HIV-positive mother could receive free formula feed directly from the nurse if the mother requested it.

Participants' understanding of how long an eligible client could be provided with free infant formula feed under the new policy varied, from thinking that this could be for a few months to up to 18 months.

In contrast, knowledge regarding the duration of free infant formula feed provision in the previous policy was generally well known:

Each and every HIV-positive mom was receiving ten tins of Pelagon every month until that baby is six months old. (P02_CNP)

4.3.1.3 Diverse views on advantages and disadvantages of new Policy

There were varying opinions on the advantages and disadvantages of the new policy.

Some HCWs were in favour of the new policy promoting exclusive breastfeeding for HIV positive mothers as they were of the opinion that this policy presented safer and healthier options for infants, especially for their first 1000 days:

So, I thought that the government has done a good job [promoting exclusive breastfeeding]. Carry on, never stop. (P07_PN)

So, the formula feed [is no longer available] we were glad because there were a lot of babies that were sick because of that [poor formula feeding technique]. (P08_CNP)

A number of participants believed the HIV MTCT risks were extremely low if the mother's viral load was suppressed:

I do think that if the viral load is suppressed, that risk is extremely negligible compared to the benefits of breastfeeding. (P09_Dr)

Other HCWs worried that adhering to the new policy might detrimentally affect HIV PMTCT. They perceived the previous policy to have been more effective in reducing MTCT risk, as there was a zero risk of HIV transmission through infant formula feeding:

Because I mean before this policy in the 2011 policy we considered those [MTCT] risks [from breast milk] that is why there was a formula feeding policy. (P03_CNP)

Some participants perceived that the risk of HIV MTCT increased with each month the baby was breastfed. Participants explained that this cumulative risk could potentially result in increased HIV transmission risk occurring in the different age groups of infants and children. This potential risk would continue to exist and may increase during the recommended 24 months of breastfeeding. As explained by one participant:

There is a lot of [HIV] transmissions, lot of different ages after 10 weeks. Till 24 months, yes we have a lot but now it is going beyond that. (P01_PN)

They expressed their concern that the new infant feeding policy was leading to an increase in HIV positive babies and was therefore detrimental to the PMTCT program. This is illustrated in the words of two HCWs:

We have quite a few positive babies from breastfeeding. (P11_Dr)

To be honest, we are sitting with more positive babies than we ever had when we were giving the formula feeds. (P03_CNP)

The main concerns of HCW holding this view were that the new policy relied on maternal retention in HIV care and good ART adherence for HIV viral load suppression to occur, which may be at odds with the reality:

Ja, I am just concerned that we are now pushing breastfeeding for two years in a population who generally does not maintain viral suppression for three years. (P09_Dr)

They viewed problems with the retention of patients in care as depending on a complexity of factors. Some of the retention in care problems was linked to patients cycling in and out of care due to multiple personal, social and contextual factors. Several expressed the view that if patients did not internalize the health education provided on the importance of ART adherence, there was a greater risk of HIV MTCT during breastfeeding. Most viewed weak health service ART retention as presenting a particular problem for effective implementation of the new policy.

They indicated that health care facilities didn't always provide regular infant PCR and maternal viral load testing and that this could lead to more babies becoming HIV positive due to MTCT via breastfeeding. They argued that this would render the benefits of the policy essentially useless in preventing MTCT. A participant expressed this view in the following way:

Then looking at how we test [for maternal viral loads] actually. We don't test every three months. So in the time frame when you think it [the viral load] is lower than detectable, [but] if it [the viral load] should spike and the mother still breastfeeds [and]

the child is not on [ARV] treatment ... the risk of [the mother] transmitting the virus was big and I think there it was, for me for myself, I am not pro [the new policy].
(P03_CNP)

Concern was also voiced about maternal retention in care due to difficulties the healthcare system faced in its ability to trace and recall mothers who disengaged from HIV and ART care:

Unfortunately, if they default we don't pick them up quickly as our default contact tracing really is pathetic. (P11_Dr)

4.3.1.4. Perceptions of reasons for infant feeding policy changes

HCWs perceived there to be a variety of reasons for the infant feeding policy changes.

A few participants viewed policy makers seeking to cut the PMTCT programme budget as behind the infant feeding policy changes. However, they viewed this as misguided, as they believed that the budget cuts ultimately created a greater financial demand on the health care services in providing lifelong ART, potential hospitalisation, increased clinic visits and a higher demand for laboratory monitoring required for infants that became HIV positive:

We cut on budgets because it is limited and that is fine but now we are sitting with a lot of positive babies... now we have actually created a very high finance need because for that baby to be positive it needs to be on ARVs. How much does ARVs cost against to a tin of Pelagon? (P03_CNP)

It is a risk of the child being positive and it is a lifetime thing. (P12_Dr)

However, most participants viewed the policy changes as occurring due to the advantages of breastfeeding, which they believed had always been well known. In the context of an improved ART program, in which all patients are eligible for lifelong ART, they argued breastfeeding should now be encouraged. Benefits cited included: greater convenience, lower costs, improved infant immunity, feeding accessibility and better potential for mother-infant bonding. Some of these reasons are illustrated in several participants' statements:

I mean breastfeeding is definitely the best option as a general rule. (P09_Dr)

It is much better for the baby and it is much better in terms of not getting infections, gastro ja. (P11_Dr)

Ultimately, despite some HCWs having reservations, most participants felt that the new policy was a good one, even though initially the changes were unexpected and created concern among many healthcare workers:

Ja well I have even forgotten that it used to be bottled milk...it was a shock when it changed but I think it was the right move. (P11_Dr)

With time you get to accept and then you see that it does work. (P10_Dr)

4.3.2 Processes of new policy implementation

4.3.2.1. Transition vs immediate policy implementation

Some participants described a transition period during which the current policy was implemented, so that HCWs could become used to the new guidelines:

So we gradually rolled out. We said we were not just going to implement because the healthcare providers needed to sort of be informed. (P01_PN)

Conversely, other HCWs perceived the policy changes as sudden and unexpected. They reported that there had been limited engagement about the changes in policy with the health facility management, HCWs or patients:

There wasn't a lot of buy in [initially] because it created such a lot of complexities (P03_CNP)

They stated that patients were merely informed during their antenatal visits of the policy change as a *fait accompli*- that 'breastfeeding was now safe' and therefore patients should not expect free formula.

The timeframe for the transition to the new policy was unclear for all participants. Most remembered that for a time mothers could decide whether to exclusively breastfeed or

formula feed. However, after a period of time, patients were no longer offered the option of free formula.

I think it changed to kind of optional and now it definitely [infant formula] is not routinely provided. (P09_Dr)

There was a shared view among the participants that the Western Cape Department of Health was hesitant to accept an immediate change in policy, and preferred to phase in the changes.

I think we in the Western Cape were a bit hesitant because we looked at the risks and we did the SWOT analysis, [and] you could see the risk. (P03_CNP)

4.3.2.2. Uneven HCW training on new policy

Some participants reported that training was provided to inform staff of the rationale behind the policy change, and the new messages that patients should receive. This facilitated acceptability of the new policy:

[I asked] How can I learn more about breastfeeding and then they said, okay they are going to give a course in breastfeeding and then I joined up there and... for one week and I learned a lot there. (P05_CNP)

Other participants stated they had never received training on the new policy and they did not realise there had been a change in the infant feeding policy until after implementation.

Later on I realized there were new guidelines. (P02_CNP)

Some participants reported that HCWs were not all being equipped to discuss HIV MTCT risk during infant feeding counselling.

Because it is not something that we talk about and in [PMTCT] training we also don't talk about it. (P01_PN)

They indicated these factors limited their ability in implementing the new policy.

4.3.2.3 A gradual ‘pathway’ to acceptance of policy changes for patients

While some participants once again recalled that HCWs initial feelings towards the policy changes were shock, fear and anxiety, over time they came to appreciate the benefits of the new policy:

Ja, I did feel shocked. I remember now and I felt anxious but in fact, it looks like it has not been a bad decision. (P11_Dr)

Most participants described the policy as becoming eventually acceptable because of the number of advantages of breastfeeding, despite some concerns remaining. They once again cited the economic and practical advantages of breastfeeding - that breast milk was free, convenient and at the correct temperature. A maternal-infant advantage of breastfeeding was that it encouraged bonding. Advantages for the infant also included acquiring maternal antibodies and necessary nutrients from sterile breast milk without the risk of contaminants. This ultimately resulted in a growing healthy baby:

The person who is going to boost the immune system is the mother’s milk whether you are positive or negative (P06_CNP)

Among some participants, the global recommendations and government policies encouraged their acceptance of the changes in policy. The global WHO and UNICEF ‘Baby Friendly Initiative’ (BFI) had been launched in 1991, with the subsequent adoption of the breastfeeding restoration plan (H164/2012) by the Western Cape DoH in 2012. The DoH aimed for all birthing units to be BFI accredited by 2016. This meant that all birthing units were to implement practices that promoted, protected and supported breastfeeding. Acceptability of the infant feeding policy was therefore supported by HCWs in birthing units (MOU) in accordance with their BFI accreditation.

Messaging that went out of certain MOUs because it was also about the accreditation: breastfeeding friendly initiative. (P01_PN)

HCWs also found the changes in infant feeding policy more acceptable due to the changes in other South African health policies, such as: access to lifelong ART for all HIV positive patients, regardless of CD4 counts; and regular viral load monitoring of breastfeeding mothers to ensure they were virally suppressed and therefore less likely to transmit HIV.

Now you are on continuous ARV, you go to take that treatment then the virus is suppressed, and you won't be able to transmit to the baby. (P06_CNP)

Participants described, however, that they would feel responsible for a HIV positive infant result, if they promoted breastfeeding while a mother had a high viral load. These participants described the conflict and distress they felt in promoting breastfeeding according to the new policy when they believed the child was at risk of HIV transmission:

I mean... it is as if I encourage the baby to become HIV positive because when it [the VL] is high, you cannot encourage them to breastfeed. (P06_PN)

The thing that I find terrible is seeing moms that have defaulted their ARVs and we have a huge number of these moms who go on breastfeeding and then the kids become positive. (P11_Dr)

Despite acceptance of the policy by participants, a reluctance to advise mothers at high risk of HIV MTCT to breastfeed, was expressed by some HCWs. This was due to experiences of previous HIV positive baby outcomes.

4.3.2.4 HCW policy acceptance when theoretically applied to own lives

Participants were asked what infant feeding policy practices they would adopt if they, their wife or daughter, was HIV positive. This question was asked as the researcher believes that an application to 'real life' often reveals the inner sentiments that HCWs have towards a policy. Views were divided on this issue.

Half of the participants reported that if they were HIV positive, they would not be willing to take any risk. This was based on the view that their socio-economic circumstances allowed them to adopt different infant feeding practice to those in the community of women they served. The quotation below reflects the sentiments of those who would be unwilling to breastfeed:

Personally I would probably not breastfeed even if I was on ARVs and my viral load has been suppressed for five years, I would probably formula feed. (P09_Dr)

Never! I would never even have dared to breastfeed. I would just have wanted to protect my child. Even if I didn't protect myself. My child is my responsibility because that is where the guilt lies because no mother wants to harm her child. (P03_CNP)

The other half reported that if they or their daughter were HIV positive, they would still promote and practice exclusive breastfeeding. However, they would do so in conjunction with strict ART adherence and infant prophylaxis provision. This is illustrated in the following quotations:

I would advise her [my daughter if she was HIV positive] [to breastfeed her baby] because she is going to be taking [ARV] medication. (P08_CNP)

If she [my daughter] was [virologically] suppressed I would recommend that she breastfeeds, ja. (P11_DR)

4.3.3 Women's ability to implement safer infant feeding choices

This section captures participants' beliefs concerning actual infant feeding practices. This was explored in the context of the factors influencing infant feeding practices. Participants believed that most women were now willing to breastfeed in accordance with the current infant feeding policy. However they retained reservations with respect to the practical implementation of the policy. They viewed the following factors as hindering or facilitating implementation: Personal factors; Maternal socio-cultural factors; and Health service-related factors. These factors frequently intersected with each other.

Generally, all participants believed that the breastfeeding rates have increased slightly since the implementation of the infant feeding policy in 2015.

4.3.3.1 Personal and interpersonal maternal factors

Participants described physical breastfeeding challenges faced by mothers, such as adopting poor breastfeeding techniques or having cracked nipples. These often resulted in patients stopping breastfeeding without consulting the HCWs for advice or support. A main reason for cessation of exclusive breastfeeding, according to participants, was that mothers frequently do not believe there is sufficient milk to satisfy the babies' needs, and they either stop breastfeeding or start mixed feeding:

We ask, “Are you still breastfeeding?” they will say, “No.” When we ask them “why not?” they say their milk was not enough or they say they went back to work.

(P09_Dr)

Breastfeeding techniques require relaxation and involve a skill to be learnt. Participants described how new mothers tend to be tense, often battling with breastfeeding, resulting in many patients giving up on breastfeeding:

If you are tense you can't. You won't be able to breastfeed and secrete enough milk.

(P06_CNP)

They just say I am not going to breastfeed or they start and they struggle and they feel, “I am not going to do this”. (P03_CNP)

The risk of HIV MTCT was regarded by most participants as an important factor influencing safe feeding practices. A poor history of ART adherence was recognized by most HCW as the main factor indicating an increased risk of MTCT during breastfeeding. Participants viewed mothers, who had previously disengaged from care and returned back into care when they became pregnant, as being at high risk for MTCT.

The defaulters – she will stop the [ART] treatment 2016, get pregnant 2019 and didn't book. She will come un-booked. (P07_PN)

The timing of booking was believed to be strongly linked to the MTCT risk, with 'late bookers' being at increased risk - either because there was limited time to suppress their viral loads or because of a late HIV diagnosis. This was compared to a patient who had booked early and had had time to suppress their viral load.

If they book early and the viral is detected early, then the viral load is suppressed early then the chances [of MTCT] is very low. (P02_CNP)

Participants felt that if the mother had not disclosed her status to her partner and family, there was a heightened risk of MTCT:

*Yes,[if] they are hiding the medication for it [HIV]. It is difficult for them [to adhere].
(P02_CNP)*

Patient health education was the key to ensuring the acceptability of the policy change to patients, according to participants. HCWs felt that clear explanations about the fact that taking lifelong ART will suppress the viral load and consequently reduce the MTCT risk, was important for patients' acceptance of breastfeeding. One participant described her explanation to mothers as follows:

You go to take that treatment then the virus is suppressed and you won't be able to transmit to the baby. (P06_CNP)

Several participants described having to 'convince' patients about the benefits and safety of the policy change:

So we would convince them of the benefits of breastfeeding and why at that [previous] time it [breastfeeding] was not encouraged. (P07_PN)

Participants described that a mother's understanding of the risk of HIV MTCT depended on the counselling she had received. Some patients were willing to breastfeed, as the reduced MTCT risk had been explained. However, maternal attributes such as education level and insight and information provided, contributed to her comprehension of the risk. Participants explained that some mothers demonstrated their comprehension of the MTCT risk by adhering to ART and maintaining a suppressed viral load, while other educated HIV positive mothers rather elected to formula feed because they saw breastfeeding as a MTCT risk, especially if they have a high viral load:

The moms that I have on track with suppressed viral loads and who come regularly and check, they are different. They know [the risk of MTCT]. (P11_Dr)

*So the more educated [HIV positive] moms they now would rather not breastfeed.
(P11_Dr)*

Participants described the desire to stop breastfeeding as an indication that some mothers continue to fear the MTCT risk:

Yes, they understand it because some of them, even if their viral load is suppressed, they are scared of continuing breastfeeding yes. (P04_PN)

We find that some of the mothers they don't even want to [breastfeed] because they do understand [that there is some MTCT risk]. [If] they don't even want to breastfeed, then we encourage them for formula feed. (P06_CNP)

Participants felt that some patients found it difficult to accept the new policy, despite the education and counselling provided. These patients were described as 'confused' and needing 'convincing' as they felt that they had received conflicting messages on infant feeding:

They were just too scared in that we were giving like conflicting information. (P10_Dr)

Patients who were previously pregnant when free formula was available, were reluctant to accept the policy change, and often elected to buy formula feed. As described by one participant:

A lot of moms came to the facilities and said, "I don't want to breastfeed. I am positive. I don't want to do this. My other child is negative because I just formula fed. So now must I do this?" (P03_CNP)

Older age was identified as a contributing factor to a mother implementing safer infant feeding practices in line with the policy. Most participants regarded young mothers as 'difficult' in terms of breastfeeding. Participants described young patients' desire to maintain their figures and a social life, despite having a baby. Hence participants identified what they saw as 'maternal independence' as a contributing factor to not breastfeeding or its cessation:

If you are breastfeeding you must always carry this baby around when you are going to chat, or wherever you are going. Whereas they can sit with their friends, they can leave the baby because it is formula fed. (P02_CNP).

Additionally young mothers were described as often partaking in social parties and alcohol consumption, while their baby was left in the care of a family member. Participants said that older family members discouraged breastfeeding if the mother drank alcohol. This resulted in the young mothers stopping breastfeeding or starting mixed feeding:

And you will find that also the old ladies, the mother outside, say you cannot breastfeed the baby while you are drinking. So they stop because they want to go for the alcohol. (P08_CNP)

Participants had varying views on whether mothers were empowered to make an informed infant feeding decision. Some felt that patients might wish to choose breastfeeding, however, despite their desire to do so, the patient's social context and personal factors made it difficult for them to implement their choice:

The human factor that comes in, that you have actually no control over, and sometimes it is the situation or the context the moms find themselves in that dictates actually what they are going to do. (P12_Dr)

4.3.3.2 Maternal socio-cultural and economic factors

The mother's socio-cultural context was thought to be the greatest factor influencing infant feeding choice.

Working mothers often needed to return to work before the recommended four months of maternity leave; some as early as two weeks post-birth (the minimum maternity leave by law). Although expressing breast milk is encouraged, participants varied in their response as to whether this was realistic for working mothers and students.

Despite breast milk expression being encouraged by HCWs, breastfeeding promotion policies at work often do not exist. Mothers battled to store their expressed breast milk in a fridge or find time to express breast milk during working hours. Travel time from their homes in Khayelitsha to work or place of study were often long and required multiple taxi changes, therefore keeping expressed breast milk fresh was not always feasible for the mothers:

I know we do advise her [the patient] to express breast milk but that is not easy in this environment where the moms might be away from their babies for 12 to 15 hours and they can't just easily express milk where they are. (P09_Dr)

Many mothers in Khayelitsha choose to send their child back to their 'home province', such as the Eastern Cape. This occurs for several reasons, including: safety concerns for the child, the mother is working or studying, or the mother has limited family support in the Western

Cape. Therefore, many participants felt that some mothers had already made the decision to formula feed before they had the child. As one healthcare provider expressed this view:

I [a patient] am not going to breastfeed this baby because I am going back to school and this baby is going to the Eastern Cape. (P08_CNP)

Participants felt that cost was an important factor influencing a mother's infant feeding decision. Participants described how unemployed mothers often can only choose to breastfeed, while other mothers simply purchase formula, if they choose to formula feed and can afford it.

I mean cost is, I think it is basically the only thing. Most of our patients are making their decision based on what they can afford. (P09_Dr)

Participants described pressure from family members upon the mother to give formula or solid food, before six months of age as a factor contributing to a mother mixed feeding. This was due to a common belief that a baby received inadequate nutrition from breast milk alone, rendering the baby hungry:

The baby will keep on crying until the mother will think or believe the baby is not getting enough [breast milk], they give [formula feed]. (P02_CNP)

Additionally, participants described a further common belief that formula milk is 'stronger' resulting in either formula feeding, to make the baby grow bigger and stronger, or mixed feeding, to ensure that the baby receives the best of both:

They think ...if you use both the baby is strong. They say what they don't know is that the stronger one is the breast milk. (P06_CNP)

An unstable home life, with poor support and frequent exposure to violence and abuse in the home or in the community, were cited as reasons which increased a mother's HIV MTCT risk and influenced a mother's ability to safely breastfeed. Conversely, they described women who had an education and who came from a cohesive family as finding themselves able to breastfeed safely with a decreased HIV MTCT risk.

HIV transmission to an infant as a factor influencing mothers' infant feeding decisions was described as multifaceted. The infant feeding choice is compounded by many factors in mothers' social and cultural lives and could increase or decrease the risk of HIV MTCT during infant feeding. Participants strongly felt that many of the socio-cultural and economic factors related to infant HIV transmission through infant feeding, were beyond the control of the patient. These factors affected the mother's personal actions and the decisions she ultimately made.

Participants believed that previously there was possible inadvertent HIV disclosure if a patient formula fed. They were assumed to be HIV positive and suffered potential stigma as a result:

It is almost like if you are not working but you are formula feeding you must have HIV. That is the stigma that is out there... I had a lot of patients elect to breastfeed because they know that if they elect to formula feed people will think that they have HIV. (P09_Dr)

Some HCWs were therefore of the view that the new infant feeding policy helped decrease the stigma associated with HIV positive mothers in the community, resulting in greater acceptance of breastfeeding by HIV positive patients:

Now they are happy to breastfeed because now they fit in ja, because everybody is breastfeeding. (P02_CNP)

Participants described a woman's intimate partner as an important influence in infant feeding choices. Partner HIV disclosure and financial support influenced the mother's infant feeding decision. Participants felt that there is a greater chance of exclusive breastfeeding if the pregnancy was planned and if the woman had disclosed her HIV status to her partner.

Additionally, HIV non-disclosure to family was seen as a contributing factor to mixed feeding. Participants described that the family 'acted without insight or understanding' when they were unaware of the mother's HIV status, often providing formula to the child while the mother was not around:

The family members because they are not involved because they don't know anything about this that the baby must not take anything because of this disclosure problem. (P02_CNP)

Participants described women who are most vulnerable to the risk of MTCT of HIV as those engaging in transactional sex for an income; single mothers without support and those who had an unstable home life. They identified the use of drugs and alcohol, as well as exposure to abuse and violence, as additional factors influencing an increased risk:

Generally it is the social problems that cause the long-time problems. (P11_Dr)

They felt that South African government interventions were needed to address these socio-economic factors, in order to curb unsafe feeding practices that contributed to MTCT of HIV.

4.3.3.3 Health system factors

Some participants viewed inadequate integration of health services as a factor that could increase HIV MTCT risk. Separation of ART services and ART patients from other service points at a facility, or patients having to access care from different sites, could result in HCW acting 'blindly' at times, with patients receiving care in silos:

We forget to ask about HIV [at the MOU]. Because a lot of our patients are getting ARVs elsewhere. (P11_Dr)

If a patient accessed HIV care or ART at a different site to that which they attended for maternal care, there would be no available medical or pharmacy records related to their HIV status. The clinician then relied on the patient to provide information so they could make clinical decisions. This required patient recall and insight into their medical condition, including blood results, diagnosis and medication. Some patients might not be able to recall these details, either because of poor understanding, poor communication of information to the patient or poor recall of all the medical details. This made follow up difficult for HCWs:

Those patients that you cannot do the follow up properly. Because there are those people who come from facility V, those people who are coming from facility U. Those

people we are not having... a way of following them up because they are not taking their medication from here. (P08_CNP)

Patients may also access ART from a service provider at a site that does not offer BANC services, and would therefore access BANC services at another site.

So I had a couple of really bad cases where people who were getting treatment in private or at another clinic, with high viral loads but nobody in our MOU had ever checked. (P11_Dr)

Participants noted that patients often chose to access ART and maternal care at different sites. They frequently accessed HIV care further from where they lived, due to disclosure concerns related to HIV stigma, but found it more convenient to access maternal care closer to where they lived. This could undermine their quality of care, as HCWs would be unable to follow up mothers and offer on going support.

A participant stated that she discouraged women from doing this:

All right why are you staying in Macassar and you come and book in Facility Y, instead of Harare that is near to you. (P08_PN)

Some participants felt strongly that mother-baby pairs should be able to access services together to ensure holistic care.

So I think this whole system where the paed's is a separate place...the integration might help for that. Where you can see a mom and a child together you know. (P11_Dr)

However, there were other participants who felt that referrals to the MOU and back to the general ART services were mostly well done. They believed that HCWs at both sites of care would generally be aware of the patient's status and viral load and could therefore provide appropriate care.

Some participants raised concern regarding patients continuing HIV care at ART adherence clubs, while breastfeeding. The ART adherence club model is designed so that patients

collect medication every two months from the club facilitators (lay counsellors). Provided patients remain stable on ART, it was assumed that they are virally suppressed and they are only required to have an annual visit to a health facility to check their viral loads. Breastfeeding club patients would therefore not be as closely monitored as recommended in terms of the WC 2018 PMTCT policy. The PMTCT policy recommends viral load monitoring every three months, for early detection of a potentially raised viral load that could result in increased risk of HIV MTCT. These participants believed that pregnant and breastfeeding mothers should not be included in the ART adherence club system.

In contrast, other participants did not see ART Adherence clubs as presenting a challenge to the viral load monitoring of pregnant and breastfeeding women. They believed that women falling into these categories were appropriately being removed from the clubs and requested to return to a health facility for ART.

Participants also perceived a decline in quality of maternal care for HIV positive women occurring due to the recent removal of the Mothers-to-Mothers organization from the health facilities. Mothers-to-Mothers is an international non-profit organization which utilises a peer-based model to support, educate and link HIV positive mothers to care.

We had the Mothers to Mothers that has now stopped, I am very sad, ja. (P11_Dr)

The contract termination of these mentor mothers was viewed as a removal of an important source of education and support for HIV positive pregnant and breastfeeding mothers.

4.3.4 HCW Infant feeding messaging and counselling

4.3.4.1 Content of infant feeding counselling message

In keeping with the infant feeding policy, most participants agreed that breastfeeding was ideally the most suitable feeding choice for HIV positive mothers. This formed the basis of the infant feeding counselling they provided. However, specific counselling content varied among participants, taking into account HIV MTCT risk and patient choice.

Some participants, reported discussing HIV MTCT risk with all patients:

I say to them there is a portion of virus going through breast... even if she is virologically suppressed. (P06_CNP)

Other participants reported that they didn't discuss the MTCT risk with patients, in the context of viral load level issues. They felt that as it was difficult to quantify the HIV MTCT risk for a layperson, it would therefore be unfair to expect the mother to make an infant feeding choice, knowing about the existence of a small MTCT risk, even if they were virologically suppressed:

I think it would make it so hard for mothers, especially you know if you say, "there is a very, very small chance [of HIV transmission]", I think that is not fair, it is horrible. (P11_Dr)

If the MTCT risk was truly being discussed and understood, participants felt there would be a greater uptake of formula feeding. The participant below explains:

[HCWs are] Probably not [discussing HIV MTCT risk], because I think we would see a lot more patients electing to formula feed if we told them. (P09_Dr)

Some participants described mixed infant feeding as inappropriate for everyone, but especially for HIV positive mothers. These participants strongly discouraged mixed feeding among mothers as per the infant feeding guidelines. Therefore, when mothers returned to work, considering the difficulties in being able to express breast milk, they would rather be encouraged to formula feed.

4.3.4.2 Importance of a patient centred approach, continuity of care and individualised counselling

Many participants reported that they felt it important to use a patient centred counselling approach when applying the infant feeding policy. However, they felt that the new policy limited this approach and at times it failed to offer sufficient flexibility to clinicians in providing patient centred care.

A patient centred approach

Participants described that, despite the guidelines and the infant feeding policy being in place, there are certain instances in which they felt a need to act beyond the guidelines in order to provide patient centred care:

So normally I don't act outside of the guidelines but if there was an indication for me to do it, I would feel no pain. I would do it. (P11_Dr)

Some participants reported that some HCWs might follow the infant feeding guidelines without thinking about a specific case that could result in an HIV positive baby. In these instances they felt it would be in the patient's best interest to act beyond the guidelines. As explained by two participants:

Most people are following the guidelines that say, 'keep the baby breastfed' and I just think we have huge gap there where we are going to see positive babies and I have seen positive babies. (P09_Dr)

If there is a chance that this baby could become HIV-positive then I would encourage formula feeding. (P01_PN)

Most participants emphasized the need to investigate the patient's context before deciding how to counsel a woman while implementing the infant feeding policy. This is so that counselling could be individualised according to the patient's circumstances:

You have to sit down with each patient, HIV positive or HIV negative. Because there are so many different things that are happening to both sides and we deal with that person, with that particular problem. (P08_CNP)

One participant described how she determined the risk MTCT of HIV according to the patient's situation:

Let me take you to for example a patient that was in labour ward having a high viral load, un-booked, drinking,that one, we cannot take that risk [in advising breastfeeding]. (P08_CNP)

The physical condition of a woman also influenced the infant feeding counselling provided. Some participants identified bleeding nipples as a reason they would advise an HIV-positive mother to stop breastfeeding. As illustrated in the extract below, individual advice included recommending to the patient to rather formula feed in these circumstances:

Yo, I will stop the breastfeeding and then encourage [her] to put the leaves, the cabbage leaves on and also put the cream and put something on [and advise the patient on] formula feeding. (P04_PN)

Overall, most participants voiced feelings of support for providing patient-centred care, and at times, using their own judgement, to act beyond the infant feeding policy guidelines.

HIV status guides counselling

Participants described the patients' current HIV status as an important determinant in shaping the infant feeding counselling provided. If a mother tested HIV negative, important aspects of counselling would include advising regular re-testing at a convenient time and at a location close to the patient to ensure they remained HIV negative. Some participants reported recommending to their patients that if possible, they should try re-testing monthly:

So, if she is HIV negative, I would probably just let her do that [mixed feed]. I would just encourage her to test regularly and I would even say to her look, 'between you and me, test monthly'. (P09_Dr)

Participants regarded newly HIV diagnosed mothers as at high risk of HIV MTCT. The importance of starting ART timeously, regular viral load monitoring and infant PEP, were emphasized for these patients. However, not all HCWs appeared to provide uniform advice on infant feeding for these patients. Some reported recommending exclusive breastfeeding, while others recommended formula feeding, if they believed the patient could afford it. The following statements illustrate these diverse counselling practices:

No I would advise the mommy to stop the breastfeeding because we don't know... because we are still going to start her with ARV and then we don't know [if] the viral load is still high because we didn't check the viral load yet. (P04_PN)

No I would tell her... at the clinic they will give the baby prophylaxis so it [breastfeeding] will be safe for you. As long as they are happy, you can also be happy but breastfeed because it is good for baby. (P05_CNP)

Viral load levels and counselling practices

Participants reported that if women were HIV positive, they tried to use the patients' viral loads to guide the counselling and care provided. However, there was variation in the counselling practices of participants. Some participants explained that if the high viral load was likely to be suppressed quickly, they encouraged breastfeeding. However, if it was an extremely high viral load, which would take longer to suppress, they encouraged formula feeding:

If the mother is having, let's say the viral load is 1,000, let's say four digits. I normally don't discourage them from breastfeeding, if the viral load but those with eight digits, one million and higher, I don't encourage them [to breastfeed]. (P06_CNP)

Other participants explained that they didn't encourage breastfeeding at all if the mother had a high viral load.

If the mom, the viral load is not suppressed, so we don't recommend the breastfeeding. (P04_CNP)

Participants who advised mothers with a high viral load not to breastfeed emphasised that patient education, support and counselling of mothers about the reason they should formula feed when they had a high viral load, was crucial:

You have to explain to the mothers why you don't want to breastfeed when the viral load is very high. (P06_CNP)

Participants described other circumstances in which they would counsel the patients not to either breastfeed or mixed feed, when her viral load remained high. However, participants made it very clear that the counselling was case-specific and the reason for the patient continuing to have a high viral load required investigation:

Advice I would give her would be very patient specific as to why she is failing [HIV treatment], what the problems are. (P09_Dr)

Participants in general felt that it was acceptable to promote exclusive breastfeeding among HIV positive mothers with a suppressed viral load. However, monitoring of the viral load was identified as essential before promoting the continuation of breastfeeding.

Participants felt that even if a mother mixed fed her infant, the risk of MTCT would be low, provided her viral load was suppressed.

Participants also reported that the viral load timing determined the advice they provided, in the knowledge that ‘early bookers’ still had an opportunity to suppress their viral load in time for delivery.

If the mother had a high viral load at 28 weeks, you can still encourage her to reach that... to be lower, to be lower by the time she gives birth. (P06_CNP)

Viral load monitoring and continuity of care as a component of patient centred care

Participants were all aware that in the event of a woman having a high viral load, the risk of transmission increased. Therefore, participants believed that, for the successful implementation and outcomes of the new infant feeding policy, viral load monitoring was essential. Participants described the three-monthly monitoring of maternal viral loads during breastfeeding (including those of mothers that had presented virologically suppressed on previous occasions), as extremely important in ensuring PMTCT:

We continue to checking the mother’s viral load every three months during breastfeeding because we want to monitor because we know there is a high risk for the chances of transmission if the viral load is high and mom is breastfeeding. (P02_CNP)

Most participants believed that reasonable efforts were made to monitor women’s viral loads according to the PMTCT and infant feeding guidelines. However, some participants felt strongly that regular follow up of viral load results to ensure VL remained low, which was essential for the new policy to be effective, was a weakness in health service provision. This resulted in HIV positive babies and led to feelings of frustration among HCWs:

So I did a viral load in February. She came back in March and no one looked at the results. She came back in April. No one looked at the results. She delivered in April. No one looked at the results. Child was given Nevirapine. She came back in June and was picked up as a defaulting breastfeeding mom with a high viral load in June. That is what drives me nuts! I presented it at the M and M. (P11_Dr)

The above extract illustrates the importance of continuity in cascade of care in the counselling and management of HIV positive pregnant women and new mothers. One participant described how they tried to prioritise the breastfeeding counselling of HIV positive mothers in the daily patient queue and try and bring patients back to the same HCW to ensure continuity of care.

If it is a breastfeeding [HIV positive] mother, I take the folder. So I try because I don't want the babies positive. I try get as many as those to see me as possible. (P11_Dr)

4.3.4.3 Responsibility for infant feeding counselling

Opinions varied among participants on who should be ultimately responsible for counselling a mother on the infant feeding options. Some believed that it should be the responsibility of the lay counsellors:

The counsellors are supposed to tell them that. They are supposed to have this education [from] antenatal right throughout because there is a group education that happens in our facilities. (P01_CNP)

Other participants believed all HCWs should be responsible for providing and supporting infant feeding counselling:

Everybody [should counsel]– because when you preach this, the counsellors preaches the same thing, the nurse preach the same thing. I mean you cannot be told one thing different ways and it cannot sit in your head. So that responsibility lies with all of us. (P08_CNP)

I personally always spend a lot of time to find out why did the person default? What was the reason and all that. (P12_Dr)

4.3.4.4 The HCW as a factor influencing safe infant feeding practices

Participants felt they played an important role in the infant feeding choice of a mother, and believed that patients valued the time, effort and information they provided:

We are important because they value what she got from the clinic and that knowledge. (P07_PN)

Most participants believed that by providing fully comprehensive information on different infant feeding options, mothers would be best equipped to make their own informed feeding choices. However, some participants believed they should more actively guide mothers on their best infant feeding options, depending on the specific context that women found themselves in. They believed this type of more directive guidance enabled mothers to make the best practical decisions, tailored to their circumstances. Several participants described a scenario of an infant being sent away to a relative, in which they advised the mother on when and how to change to formula feeding. They believed this showed an optimal patient centred approach to care:

So then they will come to me and say, “Sister my baby is going to Eastern Cape”, and I say, “fine, that means your baby is going to change to formula, okay?” (P05_CNP)

However, despite efforts to provide patients with the information to make their own infant feeding decisions, one participant believed that patients often relied on the HCW to make the decisions for them, as opposed to making informed decisions themselves:

But still they rely on you. To make a decision for them and sometimes it is difficult to use information, even evidence, you know. (P12_Dr)

Participants varied in their opinion as to whether they felt patients trusted HCWs sufficiently to inform them truthfully about the feeding practice they were actually practising. These varying participant opinions are illustrated below:

Sometimes moms are so scared of healthcare providers, in my opinion, they would just answer what they think they should. (P01_PN)

I know they trust me because they tell me constantly that they trust me and they are happy for my care. (P11_Dr)

Participants felt that feeding practices did not necessarily remain constant and although most patients were willing to breastfeed initially, after receiving counselling, many subsequently changed to formula feeding, without seeking further advice from the HCW. This is illustrated in the following statement by one of the HCWs:

When they come back for their six-day post-natal visit, the feeding option has already changed. (P01_PN)

Participants described continuity of care by the same provider as the best possible way to strengthen the provider-patient relationship, increasing trust and opportunities for mothers to ask HCWs for help. The desire to support mothers in their infant feeding practices is illustrated in the extract below:

I am not a nurse only I am just a friend of you, I am your sister. I am your everything to you. Whatever you want to say. Anything. Close that door. We sit down and talk. (P08_CNP)

4.3.4.5 Patient-centred infant feeding counselling challenges

Participants described how the challenges they faced threatened the provision and quality of individualized infant feeding counselling to mothers.

Participants identified limited time to provide in-depth individualized counselling according to the patients' context, as a recurrent challenge:

I don't have time to sit down and talk to the patient. (P08_CNP)

Participants felt that managerial pressure to constantly collect statistics on services offered, was a further challenge to providing optimal counselling to patients. One participant described HCWs work as 'data-driven' and no longer a 'patient-centred' approach in which

appropriate counselling could be provided. They believed this undermined patients' trust in healthcare providers:

They [patients] are lying to us. Why? Because they tell us what we [HCW] want to hear. Because we need to tick a box: exclusive breastfeeding. (P03_CNP)

Participants described the infant feeding policy as only providing guidelines for educating about breastfeeding. It fell short in providing guidelines on educating mothers who elected to formula feed, on how to do so safely (bottle sterilization and correct formula mixing techniques). This created a gap in the HCWs ability to provide more varied infant feeding counselling.

We are only informing about breastfeeding despite the fact that so many of our moms elect to formula feed anyway. (P09_Dr)

Some participants described the implementation of the infant feeding policy by HCWs as at times having resulted in a coercive or overly prescriptive counselling approach. Based on only counselling about exclusive breastfeeding, this was perceived as placing a lot of pressure upon the mother to follow only one infant feeding practice. Participants described how sometimes mothers are 'pushed' to breastfeed:

They [mothers] feel under a lot of pressure to really breastfeed but once they leave they would really go formula feeding. (P01_PN)

I think sometimes you find the counsellor is like set in their ways and they do it almost to a point of impunity like, 'you are a bad person [if you don't breastfeed]'. (P12_Dr)

Some participants felt that due to pressure to achieve the breastfeeding friendly facility accreditation to which they aspired, alternative infant feeding choices to breastfeeding were discouraged in the MOU setting. This promoted a prescriptive message about breastfeeding being provided to patients, whatever their context or choice, leading to mothers often making their own choices, regardless of the advice they received:

Formula feeding from an MOU perspective is not even an option and that could also be the reason why when they leave the MOU that they now decide – I am out now, I am going to buy my formula. (P01_CNP)

Participants felt that there was insufficient counselling provided to mothers postpartum, especially in the months when breastfeeding occurs.

I am not sure if there is a lot of focus post-natal in terms of adherence and breastfeeding. (P01_CNP)

Some participants expressed frustration in counselling poor ART adherent mothers with high VL, on infant feeding. Despite this being required in terms of the new infant feeding policy, they voiced concerns about the wisdom of encouraging breastfeeding in a group of mothers that they considered high-risk. These participants held the view that those that they saw as a high-risk group of mothers didn't internalise the counselling they received from HCWs on reducing their risks of HIV MTCT. One participant expressed the following rather castigatory view:

They don't care until the baby is now transmitted [tests HIV positive] and then they will start, "oh it is my fault. I should have listened". (P02_CNP)

Limited resources for promoting infant feeding choice among patients was noted, with participants suggesting the provision of multi-language patient pamphlets.

The challenge of providing patient centred care, which involved acting beyond the guidelines of the infant feeding policy, made some participants reluctant to provide formula to patients who may in fact warrant it. This was due to patients either being regarded as not meeting the official provision of formula feed criteria, or HCWs being unclear on when it might be acceptable for them act outside of the official policy:

I think what people are not familiar with is when it is valid to go outside the guidelines. (P09_Dr)

However, nurse participants felt well supported by the doctors in reaching decisions in this regard, and they generally felt able to refer those who they considered to be high-risk mothers to the doctors, who would make a decision on how best to support safe infant feeding.

Doctor participants reported feeling well-resourced in terms of contacting the HIV hotline or a district/tertiary hospital for advice and guidance on which infant feeding option was appropriate for individual patients.

4.3.5 Healthcare worker recommendations

4.3.5.1 HCW recommendation on messages and counselling

Respecting and supporting patient infant feeding choice were highlighted as an important patient centred care principle for all mothers.

Participants believed the infant feeding counselling message for HIV negative mothers should be to exclusively breastfeed, with emphasis on regular HIV testing, aimed at keeping these mothers HIV negative. Additionally, infant feeding counselling messages to HIV positive patients should be closely linked to ART adherence counselling, with emphasis on viral load suppression throughout pregnancy and breastfeeding.

Provision of formula feed recommendations varied among participants, with some participants suggesting free provision should still be allowed for HIV positive mothers who chose to formula feed:

If we [health services] can help them that don't afford to buy the formula feeding, then they must continue with the previous one and then give them the milk. (P04_PN)

In contrast, others suggested that they promote the purchase of infant formula feed by HIV positive mothers if they met the Acceptable, Feasible, Affordable, Sustainable and Safe (AFASS) criteria and could afford to buy it:

Why not, why can't we give the options to parents who can afford it you know? We tell them all the benefits and we say listen this is the benefits and we can tell them the risk of baby is point something or one percent or point two percent. (P12_Dr)

Participants believed a greater emphasis should be placed on ‘how to formula feed safely’, during infant feeding counselling if this was the chosen method. However, HCWs first needed to be aware of which infant feeding choice was actually being practised. A participant stated that with reference to the counselling, this is what she preferred to provide:

We would prefer you to come back and tell us so that we can inform you on how to safely formula feed. (P09_Dr)

In keeping with a patient centred approach to counselling, most participants believed that the infant feeding messages should realistically convey the risk of HIV MTCT, depending on a woman’s circumstances, so that the patient is able make an informed decision.

I still feel that – we [HCW] can provide all the evidence and the scientific information – [and] at the end of the day, people must have that option. (P12_Dr)

Participants recommended that regular refresher training be provided for HCWs on the PMTCT policy and infant feeding policy, with an emphasis on how to convey the HIV MTCT risk to HIV positive mothers.

4.3.5.2 HCW recommendation for greater flexibility in decision making

Some participants recommended that clinicians be allowed more discretion and flexibility to either promote formula feeding, provide free formula or make the clinical judgment themselves, as they are the frontline staff who are in the best position to holistically understand the patient:

So that is why I say, I am always next to them [the patients]. I can see who can get the formula feed and who can breastfeed. (P06_CNP)

They said that this flexibility would allow clinicians the freedom, not to have to act against the current guidelines in some cases, but rather to be able to use their clinical discretion in advising patients on infant feeding:

We can add that [flexibility] in the policy, the discretion of the clinician as well just to give you the freedom to not go against the policy. (P10_Dr)

However, other participants viewed potential complications in allowing increased flexibility of the infant feeding policy. Some participants felt it would be unacceptable to offer some patients free formula and not others, despite the patient centred approach and individual benefit. For example, HIV negative mothers would not be offered this choice, while HIV positive mothers may, raising questions of fairness and equity among patients:

*It [greater HCW flexibility] would just cause a whole lot of community [problems] if some people get free formula, some people don't get formula for free at the facilities.
(P10_Dr)*

Despite the varied recommendations regarding provision of free formula, all participants agreed that any policy reviews or adjustments that occur should ensure that all relevant policies, including the PMTCT policy and infant feeding policy, promoted the same message. Some participants recommended that a review of the free formula criteria should be conducted to expand eligibility to sick mothers, grandmothers as caregivers and mothers at high risk of MTCT, including unsuppressed VL patients on first line ART. However, other participants recommended that it would be simpler to just allow clinicians greater flexibility in applying the policy so that they could use their discretion to provide individualized care according to the patients' needs.

4.4 Conclusion

The findings demonstrate the variations in participants' infant feeding counselling. Although most participants were familiar with the new infant feeding policy, the depth of understanding and acceptability varied. The theoretical advantages of the new policy were described by all participants, however several challenges impacting policy implementation were also demonstrated. This included poor policy dissemination and an unclear rationale for policy changes, which have hampered policy implementation. Acceptance of the new infant feeding policy by HCWs, highlighted that some participants retained persistent practical concerns about HIV MTCT risks during breastfeeding, This underscored the importance of adequately addressing the feasibility and practicality of safe infant feeding, taking into account the maternal, socioeconomic and health system factors that prevail. In addition it

emphasised the need for a patient centred approach to counselling that catered for greater individualized care tailored to patient's needs.

Based on these findings, Chapter 5 will explore how these themes contribute to a greater understanding of infant feeding practices in Khayelitsha, and whether these findings are supported or contradicted by the existing literature.

Chapter Five: Discussion

5.1 Introduction

This chapter discusses and interprets this study's findings in relation to its aim of exploring health care workers (HCWs) attitudes towards infant feeding options; and their perception of facilitators and barriers to providing infant feeding guidance and counselling to HIV positive mothers. It does this against the background of the changes introduced to the 2013 South African infant feeding policy and situates this within the context of relevant comparative literature. Four key themes emerged in the findings; (1) HCW awareness, familiarity and understanding of the new infant feeding policy; (2) Processes of new policy implementation (3) Women's ability to implement safer infant feeding choices and (4) HCW infant feeding messaging and counselling. In addition, HCW participants made recommendations on the messaging and counselling and the amount of discretion HCWs should have when advising on infant feeding options for HIV mothers.

5.2 HCW awareness, familiarity and understanding of the new infant policy

Successful infant feeding policy implementation is reliant upon frontline HCWs being aware and familiar with the policy, which will ultimately result in either the acceptance or disregard of the policy. Policy implementation is multifaced, and several conceptual frameworks have been developed to analyse it, with no one single framework being agreed upon. HCWs process of acceptance of a policy facilitates its implementation (Morain & Barnhill, 2018; West et al., 2019). Van Horn & Van Meter's Model of Policy Implementation (1975) identified three essential factors for policy implementation. This included: an understanding of the policy goal; effective communication regarding the policy; and the capacity of implementers to implement the policy. The importance of these factors for successful policy implementation emerge in this study's findings and interpretations.

Participants reported that they were aware there had been changes to infant feeding guidelines in the new policy, however most felt that there were gaps in their specific knowledge of policy changes. This leads to vagueness about the specific changes. Participants reported that circulars containing detailed information on the changed guidelines were not widely disseminated to HCWs. Participants agreed in principle, that breastfeeding was the best available option for infant's nutrition, resulting in optimal infant growth and brain development. However, they held diverse views on the advantages and disadvantages of the policy's promotion of exclusive breastfeeding as the sole option, when faced with its practical implementation. Many

participants expressed confusion surrounding the eligibility criteria for HIV positive mothers to continue to be provided with formula feed, the messaging they should provide about mixed feeding and the optimal duration advisable for breastfeeding. These findings correspond to those of other studies that have shown that despite HCWs reporting familiarity with infant feeding policy guidelines, it is common for significant specific policy knowledge gaps to exist (Morain & Barnhill, 2018; West et al., 2019). These findings also speak to Van Horn & Van Meter's (1975) policy implementation model's emphasis on an understanding of a policy goal and effective policy communication as essential factors in promoting policy implementation successfully.

One participant described that she had to take proactive measures to find the updated policy and request to attend training. Trained, well-resourced committed frontline HCWs are required for successful policy implementation, as implementers need to know and understand what they are meant to be doing (Edwards, 1980). Participants viewed HCW training for implementation of the new policy, as inadequate. They reported that they and their colleagues had, for the most part, not received official training in the new infant feeding policy. Training in policy content is vital for successful policy implementation as it provides HCWs with the confidence and ability to implement the policy (Brynard, 2009). Some participants lacked the confidence to implement the infant feeding policy as they felt that training in PMTCT and infant feeding was insufficient. This contrasted with those participants who had received PMTCT and infant feeding policy training and as a result, felt confident to implement the new infant feeding recommendations.

Without appropriate training, and as implementers were unaware of policy details, they often acted individually, based on what they believed to be in the best interests of their patient. Several studies conducted in Tanzania, Papua New Guinea and South Africa, similarly found insufficient HCW training in guidelines for infant feeding counselling in the context of HIV (Leshabari et al., 2007; Mnyani & McIntyre, 2013; Vallely et al., 2013; Janse van Rensburg, Nel & Walsh, 2016). This highlights the importance of dissemination to HCWs of up-to-date information regarding infant feeding practices in the context of HIV for effective policy guidelines' implementation.

Participants felt that daily work pressure and a high patient load often resulted in training not receiving the priority it deserved. This rendered many HCWs out of date with rapidly changing guidelines and new policies. Due to service delivery pressures and operational needs, HCWs

are frequently not released for organised training. Managers need to see training as a crucial aspect of all HCW personal and clinical career development, which will ultimately positively impact the HCWs willingness to implement the policy. Once again, this speaks to Van Horn & Van Meter's (1975) policy implementation model's emphasis on building a HCWs capacity through proper training, as being essential to successful policy implementation.

5.3 Process of new policy implementation

Several participants viewed the infant feeding policy changes as having happened suddenly and their dissemination having occurred without proper consultation. This created difficulties in policy guidelines being successfully implemented. This is an issue that has arisen in other studies on policy implementation initiatives. Mwangome et al.'s (2017) study in Tanzania identified inadequate HIV policy dissemination as a factor contributing to poor policy implementation and sub optimal HIV clinical practice. This highlights the need for HCW to have effective channels during policy change development processes. Consequently, they will be consulted and invited to contribute their views, rather than being presented with new policy guidelines as a *fait accompli*.

Participants' perceptions of the changes in infant feeding policy guidelines clearly indicate the need for the transition from Policy awareness and knowledge to its implementation, to be viewed as a process. This involves providing information and allowing time for HCWs to fully understand the rationale for the new policy guidelines that they are being asked to accept and implement. The process needs to recognise the value that HCWs, as policy implementers, will contribute. This will be achieved by HCWs drawing on their prior knowledge, understanding and experience so as to interpret, construct and assign meaning to the proposed new policy (Spillane, Reiser & Gomez, 2006). Many of the participants in this study emphasised that, for many years prior to the changed policy guidelines, they had advised HIV positive mothers not to breastfeed in order to prevent HIV MTCT. In keeping with the earlier infant feeding guidelines and recommendations, many HCWs believed that formula feeding was safer and healthier for the babies, if a mother was infected with HIV. Given these longstanding recommendations on infant feeding practices for HIV positive women, HCWs needed to be provided with clear information on the scientific reasons behind the changes. They needed to acquire a clear understanding as to why the recommendations, and therefore their messages to patients on optimal infant feeding practices for HIV positive mothers, should change. In his Theory of Conceptual Change, Strike (1992) maintains that it is extremely difficult for people to make changes to their fundamental conceptual understanding, behaviours, or practices. This

theory resonates with this study's findings, in that some participants continued to believe that by encouraging breastfeeding, they were putting babies at too great a risk of HIV MTCT. These participants experienced difficulty in restructuring their prior existing knowledge.

HCW experiences with the practical outcomes of the policy contributed to how they came to perceive the value of the new infant feeding policy. Those participants who described having had no experience of HIV MTCT occurring, despite having advised HIV positive mothers to breastfeed, became more comfortable with implementing the new policy. Other participants who reported witnessing cases of babies becoming HIV infected through breastfeeding, were hesitant to recommend breastfeeding to all HIV positive mothers. Mathews et al.'s (2006) study, which examined the factors influencing HIV education provision by Cape Town teachers, found that the beliefs about the outcome of individuals' actions, influence their decision to act and implement a policy (Mathews et al., 2006). Therefore, participants who regarded HIV positive babies as a possible outcome of the policy, were less likely to feel comfortable complying with the new policy. However, participants who believed that the change in policy had led to a decrease in under age five mortality and morbidity for HIV exposed babies, were more likely to favour implementing the new infant feeding policy.

In addition to HCW personal cognitive perspectives on a policy, it is essential to recognize implementers' individual contexts. HCWs are individuals who are embedded in the organizational structure of their place of employment, such as a hospital or clinic (Spillane, Reiser & Gomez, 2006). Therefore, the policy perceptions of the participants in this study were influenced by the organizational structure in which they worked. Although all worked for the WCDoH and some worked within the same facility, different departments each had their own organizational structure. The MOU staff were familiar with the adoption of the UNICEF First 1000 days policy (UNICEF, 2017) and the UNICEF/WHO Baby Friendly Hospital Initiative (BFHI) (UNICEF/WHO, 2009), which both promote exclusive breastfeeding as a part of the holistic management of infants. Therefore, the DoH requirement that all MOUs be accredited with a BFHI status, placed pressure on the MOU management and HCWs to align their practices with BFHI status guidelines. This included promoting only exclusive breastfeeding for all mothers. Hence, this study found that participants working in the maternity and paediatric departments were more accepting of the new infant feeding policy and its advantages for optimal nutrition, growth, and bonding. In contrast, HCWs working in the general ART service, who were not as familiar with the First 1000 days policy (UNICEF, 2017) and the BFHI (UNICEF/WHO, 2009), tended to be more concerned about the possible outcome that

implementation of the new policy would result in, namely that there would be more HIV positive babies or children.

5.4 Factors influencing women's ability to implement safer infant feeding choices

Despite the new Infant Feeding policy generally being implemented by HCWs, the success of the policy's implementation was also dependent upon the patients' policy acceptance. A mother's acceptance of breastfeeding her infant has multifactorial influences. Many South African mothers have a high risk of HIV MTCT, which this study identified as a contributing factor to the acceptability of breastfeeding by patients. Participants identified several other factors which influenced a mother's ability to breastfeed. Most participants highlighted the need to therefore adapt the infant feeding counselling messages according to specific maternal circumstances in order to allow for informed decision making. In accordance with other research findings, this study identified maternal socio-cultural factors as key in influencing infant feeding practices (Chinkonde, Hem & Sundby, 2012; Risenga, 2017). Additionally, as has been found in other studies (Goosen, McLachlan & Schübl, 2014; Adeniyi et al., 2019), participants in this study recognised maternal circumstances such as employment, academic studies and travelling away from home, as influencing mothers' ability to breastfeed. Social stigma and community perceptions were also identified in this study as important factors influencing infant feeding practices. Other South African studies have similarly identified these factors as impacting on infant feeding practices (Nor et al., 2012; Ijumba et al., 2013).

This study identified several other main maternal factors (poor ART adherence; late ANC bookers; non-disclosure; young mothers), as well as health system factors (poorly integrated health services; viral load results not reviewed timeously), as contributing to the risk of MTCT. Other studies have also identified late ANC bookings as a contributing factor to increased HIV MTCT risk (Fitzgerald et al., 2010; Hardon et al., 2012; Mugwaneza et al., 2018). Poor maternal viral load monitoring and disjointed health services have similarly been found to hinder MTCT elimination (Goga et al., 2018; Mugwaneza et al., 2018).

5.4.1 Maternal attributes

Maternal attributes influencing early breastfeeding cessation were identified in this study. Participants considered young mothers as at particular risk of potentially unsafe infant feeding practices. They maintained that these mothers were more likely to drink alcohol and care about their body image. They viewed them as therefore unlikely to wish to exclusively breastfeed or remain compliant with their ART medication. Individual maternal attributes have been

described as influencing mothers' infant feeding decision-making in a number of other studies. Emmanuel's (2015) literature review of a number of studies found that vulnerable young mothers, who lack financial and social support, engaged more frequently in riskier health behavior (for example, sex work, intoxication, unprotected sex) and were more likely to stop exclusive breast feeding and practice mixed infant feeding (Emmanuel, 2015). Nevertheless, his literature review concludes that maternal age as a contributing factor to breastfeeding patterns differs from place to place. It is therefore important that HCWs understand how age affects breastfeeding practices within their own local contexts (Emmanuel, 2015). Other South African studies (Onono et al., 2014; Siziba et al., 2015; Risenga, 2017), similar to this study, have identified maternal attributes such as young maternal age, educational level and non-disclosure of HIV status, as influencing breastfeeding practices.

Study participants viewed maternal beliefs that breast milk was insufficient for proper infant nourishment, as contributing to exclusive breastfeeding cessation and either mixed feeding being introduced or mothers changing to formula feeding. A study conducted among HIV positive mothers in Johannesburg in South Africa, similarly found that the belief that breast milk provided insufficient infant nourishment, was one of the top three reasons for exclusive breastfeeding cessation (Chaponda, Goon and Hoque, 2017). Balogun et al's. (2015) systematic review of 25 studies conducted in 19 countries found that the perception of breast milk as insufficient for a baby to be well nourished, was a pervasive finding in all studies reviewed. A number of other studies also support these findings (Mahgoub, Bandeke and Nnyepia, 2002; Chaponda, Goon and Hoque, 2017).

This study found that conflicting messages from family and HCWs and different infant feeding advice provided during previous pregnancies, resulted in maternal confusion regarding the new infant feeding policy. Similarly, West et al., (2019) reported mixed messages leading to confusion and as a contributing factor to poor uptake of breastfeeding in a recent South African study. Additionally, this study found that a mother's fear of HIV transmission to the baby while breastfeeding and receiving unclear HIV MTCT risk messages, resulted in maternal misperceptions and distrust of the new infant feeding policy. This occurred particularly among mothers who had given birth to a baby in the past when formula feeding for infants had previously been recommended for all HIV positive mothers. Other studies conducted in Kenya and Uganda have reported similar findings (Kimani-Murage et al., 2015; Okonya et al., 2017).

5.4.2 Maternal setting

Sociocultural factors, such as food insecurity, lack of knowledge and socio-cultural myths, have all been identified in other studies as factors which influence the practice of exclusive breastfeeding (Mlay, Keddy and Stern, 2004; Agbo et al., 2013). The findings from this study resonate with the findings from other studies. Many participants felt that the cost of having to buy formula did not, in practice, allow formula feeding to be a choice that most mothers could make. This is supported by studies, that also found the cost of formula to be a factor militating against mothers having a choice to formula feed (Morain and Barnhill, 2018; West et al., 2019b). A proposal to exclude VAT (value added tax) from formula feed in South Africa has previously been tabled to reduce the cost of formula feed. This would allow women who chose to formula feed, to practice her chosen infant feeding method, without cost undermining her decision. However, the Independent Panel of Experts for the review of zero rating in South Africa (2018) rejected this proposal due to several factors. This included a concern that the breast milk substitute industry in lower income countries, would promote formula feeding as the optimal, normal infant feeding practice. This would undermine the policy decision South Africa took in 2011 to promote breastfeeding as a part of the strategy to curb malnutrition.

The necessity to return to work while their babies were still young was identified in this study as presenting a challenge for many mothers to continue breastfeeding. Some mothers opt to send their babies to relatives in other South African provinces, while others find childcare in their community. The rationale for sending babies to relatives was not explored in detail in this study. However, participants described young mothers who wanted to continue their studies or wanted to return to work as often sending their child to a mother or mother-in-law who lived elsewhere. A lack of facilities at workplaces, schools, and higher institutes of learning, where women could express breast milk, was described as contributing to early breastfeeding cessation. Pillay et al's., (2018) study among teenage mothers in KwaZulu Natal, South Africa, found that returning to school after having a baby resulted in early breastfeeding cessation.. Maternal employment and the necessity to return to work have been reported in another South African study as a major factor for early cessation of breastfeeding (du Plessis et al., 2016). Despite legislation to extend the period of maternity leave and ensure an enabling breastfeeding environment in the workplace (Office, 2011), many mothers form part of the informal South African workforce. Therefore, they do not benefit from these protective legislative measures, including access to the unemployment insurance fund (UIF) during maternity leave. Additionally, many mothers in formal employment, who are entitled to claim a percentage of

their monthly wage from the UIF as a maternal benefit, may still frequently return to work very soon after delivery. This may be because the partial wage maternal benefit from UIF is insufficient to meet their financial needs. Hence, they return to work in order to receive their full wage. Horwood et al.'s (2019) study among mothers working in the South African informal sector as either a domestic worker or informal trader, confirmed these findings. The most common reason for breastfeeding cessation was the need to return to work. Both informal workers (not eligible for UIF), and domestic workers (eligible for UIF), reported food insecurity as the reason to return to work and resume full pay.

Apart from the practical problems, mothers who needed to return to work face challenges in expressing breast milk, and participants had conflicting beliefs on whether mothers found it acceptable to express breast milk at work. Some believed that mothers were willing to express breast milk, while others did not believe they found it acceptable. These latter participants also mentioned the excessive length of time taken to travel home, no facilities to privately express breast milk or no appropriate breast milk storage facilities, as hindering factors. Limited research is available on how acceptable it is for mothers to express breast milk at work and thus it is difficult to reach any conclusions on this issue. Okonya et al., (2017) found in their study among working breastfeeding mothers in Uganda, that while many of their respondents were knowledgeable about how to express breast milk, they lacked knowledge and information on correct refrigeration and freezer storage of expressed breast milk and safe use of expressed breast milk. This included how long it could be kept before use.

Maternal family and community social support were also identified in this study as important influencing factors on breastfeeding practices. Many participants felt that mothers who lacked family emotional support experienced difficulty in breastfeeding. These findings are supported by other studies. In a study by Kimani-Murage et al., (2015) among woman of child bearing age, community health workers, community leaders and village elders in Kenya also identified maternal support from both family and community as contributing to both a mother's ability to breastfeed and to lengthen the duration of breastfeeding. Similarly, Emmanuel's (2015) literature review of factors positively influencing breastfeeding, supported these findings. Conversely, both studies found that a lack of social and professional support postpartum was associated with poor breastfeeding uptake and continuation.

Women's' intimate partners were identified in this study as influencing both ART adherence and safe infant feeding practices. Belay & Wubneh's (2019) systematic review of Ethiopian

HIV positive mothers infant feeding practices, likewise found that HIV disclosure to the partner ensures safer infant feeding practice. This is because the HIV positive mother receives adequate care, support and time to breastfeed. However, participants in this study viewed disclosure of a mother's HIV status to an intimate partner as challenging for many Khayelitsha women. This made it difficult for them to ensure safe infant feeding practices. This finding was confirmed by another recent study among HIV positive mothers in Khayelitsha (Stern et al., 2017).

5.4.3 Maternal choice

Participants gave a varied response to whether patients were able to make knowledgeable choices about infant feeding. Some participants believed that mothers were well informed and were able to make informed decisions. Two African studies conducted among nurse-counsellors and HIV-positive mothers in Tanzania and Ghana, respectively, have described mothers' choices of infant feeding as being associated with them being able to make informed decisions (Leshabari et al., 2007; Laar et al., 2009). However making informed decisions requires an individual to use all relevant information available, including the advantages, disadvantages and all possible consequences of their decisions. (Bekker et al.,1999). In applying these requirements to the South African PMTCT context, an informed decision on infant feeding can only be made by an empowered HIV positive mother. That is to say that she has received infant feeding counselling and adapted it to her social and cultural situation. Many of the study participants believed that some mothers were unable to make informed decisions due to inadequate counselling and challenges in their social contexts.

Participants believed that most HIV-mothers desire to adhere to ART and suppress their VL. Virological suppression is essential for safe infant feeding. It contributes to a mother's informed decision regarding her ability to practice safe infant feeding. This finding is in keeping with Horwood et al's., (2019) recent study in Kwa-Zulu Natal, South Africa among HIV positive mothers who were strongly motivated to adhere to ART so as to prevent their infants from acquiring HIV. However, participants in this study were also of the view that for some mothers, comprehension of the importance of ART adherence and HIV MTCT risk was poor for several reasons. This includes HIV counselling received, a young age and non-disclosure resulting in poor family support. Two studies conducted in South Africa and Kenya among HIV positive mothers found poor maternal comprehension of MTCT risk may occur among some mothers,, especially where maternal stress, non-disclosure, denial and stigma, contribute to poor ART adherence (Mephram et al., 2011; Kohler et al., 2014).

5.5 HCW infant feeding messaging and counselling

5.5.1 The Infant feeding messages provided

Most study participants believed that in general, HCWs promoted breastfeeding as the optimal nutritional infant feeding option. However, some participants reported that there were times that the messaging and counselling was adapted, so that it could be tailored to the patient's personal or social context or clinical condition. A study in Soweto, South Africa, found amongst HCWs, that they only promoted breastfeeding in a uniform manner to prevent MTCT for all women, regardless of their known HIV status. Rather than the nutritional benefits of breastfeeding being mentioned, HCWs were unable to adapt the infant feeding message for uninfected HIV mothers (Nieuwoudt and Manderson, 2018).

Although this study found that participants reported to be familiar in an overall sense with the new infant feeding policy recommendations, discrepancies in knowledge emerged during the interview discussion. This included, for example, when to recommend to HIV positive mothers that they should stop breastfeeding, or what to do in the event of a high maternal viral load. Participants also acknowledged that changing guidelines, insufficient training, and difficult cases may result in varying infant feeding counselling messages being provided by different HCWs. These findings are similar to another study conducted among women attending antenatal care in Johannesburg, South Africa, which found that a variety of messages were sometimes provided by HCWs who were unsure of the latest guidelines and recommendations for infant feeding counselling and HIV prevention (West et al., 2019b).

5.5.2 The infant feeding counselling process

The influential role that HCWs play in mothers' infant feeding practices found in this study, has been well documented in several other studies. Studies conducted among mothers and HCWs in both high income countries (Canada and England) and low income countries (Democratic Republic of Congo and Kenya), found that HCWs may either play a potentially negative or positive role in influencing women whether or not to exclusively breastfeed (Lamontagne, Hamelin and St-Pierre, 2008; Maman et al., 2012; Nabwera et al., 2017). Factors influencing HCWs ability to provide quality patient-centred counselling identified in this study, included having the time necessary to counsel properly, as well as all cadres of staff being provided with the necessary training in infant feeding guidance. Task shifting from a higher to lower cadre of staff is a common practice in South Africa, with lay counsellors assigned to

provide patient counselling, including on infant feeding. This has been with the aim of alleviating the workload of nurses and doctors. However, for this to be successful, adequate training and ongoing support for the lower cadre of staff, is needed. This is supported by other studies that have reviewed the requirements for positive outcomes when task shifting counselling on infant feeding to counsellors and community workers in low- and middle-income countries (Diallo et al., 2011; Jolly et al., 2012; Coutinho et al., 2014).

The need for continued post-natal support from HCWs was also identified in this study as essential to the success of promoting exclusive breastfeeding. Participants advocated for the implementation of post-natal clubs for HIV positive mothers for this purpose. The need for ongoing breastfeeding support identified in this study is supported by a meta-analysis of 47 studies conducted in low- and middle-income countries. These studies found that peer-support groups for mothers are effective in increasing the duration of exclusive breastfeeding (Shakya et al., 2017). Similarly, Younes et al's., (2015) study in Bangladesh among post-partum mother groups found a significant increase in exclusive breastfeeding due to improved breastfeeding knowledge and the fostered familiar support from the mother support group.

Patient choice was emphasized in this study as being an important component of infant feeding counselling. Although most participants reported that they adopted a patient centred message and approach in their counselling, they acknowledged that some HCWs took a prescriptive messaging approach, especially when counselling HIV positive mothers. Other studies among HIV positive mothers in Ethiopia and South Africa have reported similar findings. They reported that mothers were sometimes pressured to breastfeed, without counselling and only alternative infant feeding options being provided (Laar, 2014; Horwood, Jama, et al., 2019b). Buskens and Jaffe's (2008) ethnographic research conducted in Swaziland, Namibia and South Africa found that while in theory counselling content was meant to be non-directive and patient-centred, in practice it often became prescriptive information-based health advice.

In this study, participants believed that some mothers (e.g. mothers with high viral loads) would be better advised to formula feed rather than breastfeed, in the interests of preventing HIV MTCT. Therefore, some respondents felt that by removing free formula as an option for HIV positive mothers, HCWs were constrained in recommending this as an infant feeding option for these mothers. Although in theory, in the context of this study, counselling was meant to be patient centred, as in other studies (Buskens and Jaffe, 2008; Desclaux and Alfieri, 2009;

Nieuwoudt and Manderson, 2018), this proved difficult when only one infant feeding option was recommended in the guidelines for counselling HIV positive women.

5.5.3 Factors influencing counselling content

Patients' social context, HIV status and VL level were described in this study as a key influence on the infant feeding counselling content provided. However, participants reported that the limited counselling time available to sufficiently explore the patients' individual, health and social context, was an obstacle to patient centred counselling. Similar findings were reported in another South African study conducted among HIV positive mothers (Chaponda, Goon and Hoque, 2017). Chaponde et al.'s (2017) study also found that HCWs were constrained in exploring the patients' social and economic circumstances and relied on maternal HIV status to determine the counselling message content they provided to mothers.

HCWs perception of HIV MTCT risk was a further factor impacting on the counselling message provided in this study. Risk of HIV transmission through breast milk was well understood by most study participants. The majority reported that virologically suppressed mothers, adherent to ART, were unable or highly unlikely to transmit HIV through breastfeeding. However, virologically unsuppressed breastfeeding mothers posed a risk of HIV MTCT. A few participants still retained this fear of HIV MTCT despite VL suppression, which was illustrated in the theoretical question about whether they would practise or recommend breastfeeding if they themselves or their daughter were HIV positive. Despite studies which found that maternal ART initiated before pregnancy and continued maternal viral load suppression has been associated with zero risk of HIV MTCT (Mandelbrot et al., 2015; Blanche, 2020), half of the participants would not recommend or practise breastfeeding if themselves or their daughter were HIV positive. Tuthill et al.'s (2015) literature review of challenges faced by HCWs offering infant feeding counselling in sub-Saharan Africa found that HCWs often retain fear of HIV MTCT and transfer their own fear and personal belief that HIV transmission can occur while breastfeeding..

Factors which HCWs believed contributed to an increased risk of HIV MTCT in this study included poor retention of ART patients post-partum, a divided health care system and poor clinical monitoring during the breastfeeding months post-delivery. Poor ART adherence and retention in care of HIV positive breastfeeding mothers as a factor for increased risk of MTCT, is well documented in other studies conducted in South Africa (Lazarus, Struthers and Violari, 2013; Landon Myer et al., 2017a). Similarly, other South African studies have found that

adherence to ART and clinical attendance during the antenatal period is better than during the postnatal and breastfeeding period (Henegar et al., 2015; Hoffmann et al., 2016). Maternal disengagement from health care during the postnatal period will result in poor ART adherence, and diminished ART and infant feeding support from HCWs, thereby increasing the risk of unsafe feeding practices and MTCT.

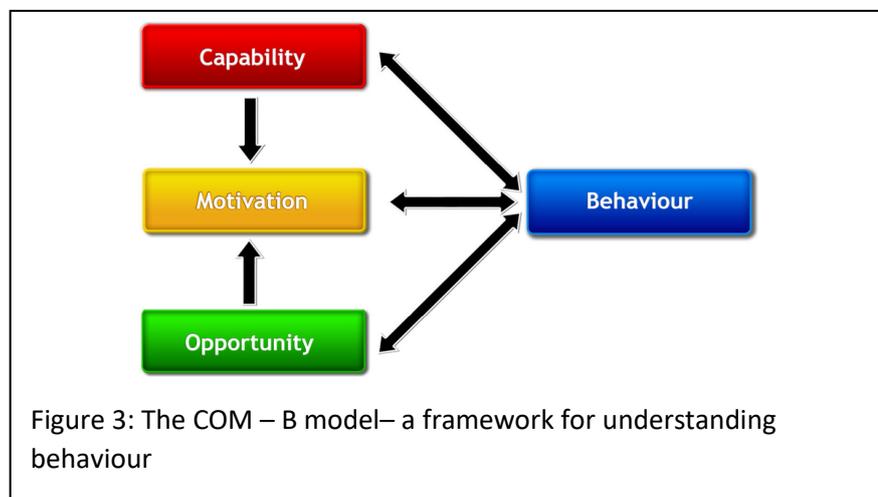
A divided health care system (ART services provided separately to BANC services), was cited by participants as a possible contributing factor to increasing the MTCT risk among breastfeeding women, as it made clinical monitoring follow up of HIV positive mothers more difficult. Previous studies conducted among HIV positive patients and HCWs in both South Africa and Zimbabwe have found that the division of health care services negatively impacts ART adherence and clinical monitoring of ART patients, in both antenatal and postnatal patients (Kagee et al., 2011; Erlwanger et al., 2017; Goga et al., 2018). Integration of health services and adapting the ART delivery model for mothers was identified in this study as being a possible factor which could strengthen safe infant feeding practices and reduce the MTCT risk. Similarly, Meyer et al's. (2017b) cohort study showed superior VL and ART adherence outcomes among South African HIV positive women attending support groups compared to those receiving standard care. The decision to access different sites for HIV services and BANC (to avoid stigma), is within the patients' right. Only by addressing the upstream factors, including the HIV stigma, will this issue of division of health care services, be resolved.

Maternal high VL was an additional factor identified as influencing the infant feeding counselling content in this study. Participants highlighted the need to strengthen ART adherence by mothers with high VL as well as counsel on the importance of VL monitoring. They additionally identified weaknesses in some health services in ensuring that the required regular maternal VL monitoring was conducted. Rollins and Coovadia's (2013) research findings confirm the need for enhancing maternal ART adherence and ensuring regular VL monitoring. This is to ensure that the infant feeding policy guidelines for HIV positive mothers are successfully followed.

5.5.4 HCW as a factor influencing infant feeding choice

Participants identified HCWs as playing a significant influential role in maternal infant feeding decision making. This is supported by several other studies conducted among mothers in African countries such as Tanzania, South Africa, Ethiopia, that have also identified the

influential role that HCWs play in infant feeding decision making (Leshabari et al., 2007; Hazemba and Ncama, 2015; Demissie et al., 2016; Chaponda, Goon and Hoque, 2017; Adeniyi et al., 2019). However, as mentioned earlier, participants felt that the ability of HCWs to play this role effectively in their infant feeding counselling, was compromised by high patient loads and limited resources. Fadnes et al's. (2010) study among mothers in the Western Cape, South Africa, also found that HCWs excessive workload threatened the quality of their infant feeding counselling. Participants described HCWs previous experiences as a contributing factor to the infant feeding counselling they provide. These experiences included both positive and negative experiences. One participant recalled encountering an HIV positive baby, despite good maternal ART adherence, which they admitted influenced the infant feeding message they provide. Another participant described witnessing an improvement in under-five mortality within the clinic since the implementation of the infant feeding policy, and thus fully supported the infant feeding recommendations made by the policy. Tuthill et al's. (2015) literature review of studies of HIV positive women in sub-Saharan African countries and Moussa et al's. (2010) study among HCWs in Niger both found that HCW personal beliefs and past experiences were prominent influencing factors in the care and counselling they provided to patients. HCWs have previously been described as gatekeepers of the infant feeding policy in South Africa (Doherty et al., 2006). This highlights the importance of HCWs acceptance of the new infant feeding policy. This was reliant upon their familiarity with and perceptions of the feasibility of the policy's implementation and impacted on their ability to change some of their clinical practices and behaviour. Michie, van Stralen and West (2011) describe in their COM-B model, that a person's capability, opportunity and motivation interact with each other to result in the adoption of a specific behaviour. The COM – B model presented in figure 3 below, has been applied in several other contexts, including in examining the factors which impact patients' behaviour in relation to medication adherence (Jackson et al., 2014) and adult hearing aid use (Barker, Atkins and de Lusignan, 2016). However, it has not yet been used in understanding HCW behaviour when



implementing the infant feeding policy. When applied to understanding HCWs decisions to implement or not implement the new infant feeding policy guidelines, it may be useful in understanding the manner in which HCWs physical (e.g. available time) and psychological (e.g. comprehension of MTCT risk) capabilities, in combination with their ability to utilise reflective (e.g. belief in the policy) and automatic (e.g. fear of HIV positive infant) opportunities which influence their counselling behaviour and advice. These factors, in combination with physical (e.g. NDoH infant feeding policy) and social (e.g. MOU organizational beliefs) motivators, result in their ultimate decisions to implement or not implement the policy. HCW counselling behaviour and decisions to implement the infant feeding policy recommendations may alter according to the influence of these factors .

Participants identified cases in which HCWs had used their clinical discretion to act beyond the policy counselling guidelines in recommending formula feeding during their counselling of HIV-positive mothers. Two scenarios of HCW infant feeding counselling concern were described in this study 1) for mothers with high maternal VL, either at delivery or during breastfeeding and 2) in the case of late ART initiation in mothers, either at delivery or during breastfeeding. These two scenarios were linked to HCWs concern regarding when maternal ART was initiated and how long ART adherence would take to suppress the mothers' VL - during a time when the risk of HIV transmission through breast milk is high. This is in line with other study findings and recommendations that maternal ART treatment is not immediately protective, therefore the baby is still at risk of MTCT during the period that ART is busy suppressing HIV replication (Blanche, 2020). Therefore, some participants recommended formula feeding as the best infant choice, while the HIV virus was being suppressed. This finding is similar to Adeniyi et al's., (2019) findings among HIV positive mothers in the Eastern Cape, South Africa, in which some HCWs advised mothers to formula feed rather than breastfeed if they had a high or unknown VL. As previously mentioned, this decision by participants to act beyond the guidelines was primarily influenced by previous clinical experiences and by HIV-positive baby outcomes. Participants felt that providing patient centred care that considered the patients' context, required them to act beyond the infant feeding counselling guidelines. The majority of the HCWs in this study were in favour of more flexibility in the guidelines, to manage HIV positive mothers according to the patients' context and ability to provide or access safe breast milk substitutes. This is in contrast to a recent study conducted in Tanzania amongst HCWs responsible for implementing HIV care.

Mwangome et al., (2017) found that, in their recommendations, HCWs requested HIV guidelines to be clearer for difficult patient scenarios.

5.6 Limitations

As this is a mini-thesis, the sample size of HCWs interviewed was small and limited to one geographical area within the Western Cape, namely Khayelitsha. Data was collected from three PHC facilities and only three different cadres of HCWs in Khayelitsha. Participants were purposively sampled, in line with qualitative methods and efforts were made to recruit HCWs of different backgrounds, cadres, and experience. The nature of qualitative research is to produce findings that provide in-depth insight into specific issues. Hence, the study findings cannot be seen to represent the views and perceptions on the implementation of the new infant feeding policy and on the infant feeding counselling behaviour of all HCWs in public sector health services, either in Cape Town or elsewhere in the country. Strategies to ensure rigour and credibility were implemented and a detailed description was provided on the methods used to conduct the study. Nevertheless, caution should be used when transferring findings to other sites. Despite these limitations, the insights gained are likely to be valuable in guiding other researchers who may wish to conduct similar research in other settings.

Chapter Six: Summary and Recommendations

This chapter provides a summary of the background to and the key findings of this mini-thesis. In addition, it presents several recommendations aimed at enhancing South African public sector healthcare infant feeding advice, which is provided to pregnant mothers living with HIV.

6.1 Summary

This study explored the attitudes of health care workers (HCWs) towards infant feeding options, perceptions of facilitators and barriers, and guidance for HIV positive mothers concerning safe infant feeding practices for infants less than 12 months of age. The research was conducted against the background of counselling and care revisions introduced through the 2013 South African infant and young child feeding (IYCF) policy and its 2017 amendments. The changes included guidelines for public sector healthcare workers when counselling all mothers, including those living with HIV, to exclusively breastfeed their infants until 24 months of age, followed by the gradual weaning of infants. Free formula feed was no longer offered as an option for HIV-positive mothers attending public sector services. It could only be provided in circumstances in which an HIV positive mother met certain limited eligibility criteria.

The study found that while most HCWs were familiar with the overall intentions of the new policy, specific knowledge of its details and acceptability, varied. Most HCWs supported the advantages of the new policy in theory. However they experienced numerous challenges in policy implementation. This included poor policy dissemination and an unclear rationale for policy changes. Lack of training in the policy for some HCWs led to them feeling ill equipped to implement the new guidelines. HCWs who had attended both infant feeding policy training and PMTCT training were more familiar and confident in their infant feeding counselling and messaging to HIV positive mothers. Workload pressure resulted in limited time with patients and was felt to undermine the provision of quality infant feeding counselling.

All HCWs emphasised the importance of adequately addressing the feasibility and practicality of safe infant feeding, taking into account a multitude of maternal, socioeconomic and health system factors that prevail. They cited employment challenges, interpersonal violence and cultural factors, which influenced mothers' ability to breastfeed. Stigma and non-disclosure was a pervasive challenge to safe infant feeding and maternal physical and

mental health. They saw addressing these factors as beyond the scope of HCWs and the Department of Health's policies and in need of 'upstream' government interventions.

Over time, most HCWs came to accept the new policy, as they saw that encouraging breastfeeding for all infants, including HIV exposed infants, brought about improvements in under-five mortality and morbidity rates. However, some HCWs retained persistent practical concerns about HIV MTCT risks during breastfeeding due to their view that there had been an increase in HIV positive infants among specific groups who they saw as 'high risk' HIV positive mothers. These included mothers who were disengaged from care, had poor ART adherence or booked late for antenatal care. HCWs believed that mothers at high risk of HIV MTCT should be regarded as special cases, who needed to be evaluated on an individual basis for eligibility to receive free formula feed. They therefore highlighted the need for a patient centred approach to counselling that catered for greater individualized care, tailored to the patient's specific needs and contexts.

The findings suggest that a 'one size fits all' infant feeding policy imposed too many limits on patient infant feeding choices and HCWs counselling content. This had the potential for HCW infant feeding counselling to become a prescriptive information session, rather than patient centred interaction. HCWs recognised that they played a crucial influencing role in mother's infant feeding choices; this impacts on promoting safer maternal infant feeding practices. Some HCWs reported that they found it difficult to rigidly adhere to the guidelines and were utilising their discretion in difficult cases, such as not promoting breastfeeding for mothers with high viral loads. Most participants felt they needed to be allowed to exercise increased clinical discretion in their infant feeding counselling and care for HIV positive mothers.

6.2. Recommendations

Given the pivotal role HCWs play in influencing maternal infant feeding decision making, it is important for policy makers and managers to understand how HCWs interpret and experience the infant feeding guidelines. The recommendations provided below are therefore aimed at contributing to the possible reconsideration of aspects of the infant feeding counselling and guidance that is offered to HIV positive mothers. They are proposed in the interest of improved implementation of the infant feeding policy and assisting in the continued success of the prevention of mother to child HIV program.

6.2.1 Improved dissemination of policy updates and training

Policy dissemination and training within a large organisation, like the Department of Health (DoH), is a mammoth task. Traditional methods, employed to reach as many HCWs as possible, include large didactic training sessions, training a trainer and emailing the new policy to HCW management for further dissemination. However, in the era of innovation and modern technology, health policy training could be provided on diverse platforms, including online learning.

The use of short succinct messages should be considered to keep HCWs up to date on changing policies and information. In the digital era, information overload needs to be avoided. Therefore, these messages should be adapted to the varied needs of HCWs, appropriate to the department in which they work. This can be achieved using information already available on the human resource Personnel and Salaries (PERSAL) management system, currently being utilised by the Department of Health. HCWs could be encouraged to also sign up for additional relevant communication and information. Further research in collaboration with program developers should examine the use of Smartphone Apps as a device to provide up to date information on changed guidelines and government policies.

Traditional techniques for information dissemination should at the same time be strengthened – including updating the staff room bulletin board by posting new policies. Arising from this study's findings inadequate training on the IYCF policy was identified. Clarity therefore needs to be provided to all HCWs regarding mixed feeding messages and the recommended duration of breastfeeding for people living with HIV.

Identification of staff members for training should be planned by management to ensure that different cadres are represented across the different departments. Staff members who have been trained should train the remainder of the staff.

This study highlights the different information regarding infant feeding being provided at different points in maternal care. An infant feeding health information package should be developed in conjunction with the training conducted. Although exclusive breastfeeding should be promoted, advice regarding safe formula preparation and workplace rights, should also be included. This could form part of the maternal case record or IEC printed material provided at antenatal bookings.

6.2.2 Policy alignment and strengthening

HCWs are responsible for implementing multiple policies; these are dynamic and change when evidence suggests this. It is vital that these policies are not viewed in silo, but are rather understood as the policies contributing to the continuum of care for any patient.

The HIV testing policy needs to be prioritised to ensure that HIV negative mothers retain their negative status – ensuring that there is no risk of HIV MTCT. The ‘same day’ ART initiation policy, for all pregnant and breastfeeding mothers, needs to be followed, to ensure timely suppression of HIV and support for newly HIV diagnosed mothers. The ART monitoring policy needs to be better implemented and strengthened, to ensure that viral loads are taken, reviewed and acted upon, as per the guidelines. This would reduce the risk of HIV MTCT through early identification of high-risk mothers. If these policies are understood and adhered to by HCWs, and risk of HIV MTCT is reduced, the Infant feeding policy is likely to be implemented, with less chance of HCW personal beliefs and fears impacting their acceptance of the policy.

In addition, future studies need to examine what workplace policies are in place to support breastfeeding mothers, whether they are being implemented, and if they are acceptable to working mothers. Collaboration between the private and public sectors should be encouraged, in order to improve infant feeding practice in the workplace as per South Africa’s Basic Conditions of Employment Act of 2014.

6.2.3 Patient retention in care

The health care system needs to recognize that the health ‘journey’ of a chronic patient, including people living with HIV, is not linear, but rather cyclical – with patients engaging and disengaging in care during the ‘journey’. Disengagement occurs due to the dynamic nature of life, unexpected events, and simple fatigue within the health care system. By understanding and preparing patients and HCWs for the anticipated journey in care, safer disengagement can occur when events beyond the patient’s control, occur. HCWs can provide mothers with empowering tools to stay in care, especially during the crucial period of breastfeeding. However HCWs must first acknowledge and normalise the challenges of adhering to medication, attending the clinic as well as managing a new baby. Further studies (qualitative and quantitative) need to be conducted on the barriers to retention in ART care and the facilitators of disengagement from care of breastfeeding mothers.

Post-natal support groups should be expanded for all mothers, to ensure regular HCW and peer support. These support groups can assist in promoting the First 1000 days initiative, including baby stimulation, a good breastfeeding technique, peer support and adherence to ART medication.

6.2.4 Patient centred care

Lastly patient centred care and individualized management, according to the patient's context, needs to be strengthened. Many HCW, who interact directly with the patients and are responsible for providing patient centred care, require a certain amount of discretion when it comes to counselling as well as management of a patient. As was found in this and other studies, infant feeding counselling messages, are often not tailored to the specific patient's attributes or context. Most patients have been found to accept exclusive breastfeeding, however, certain circumstances and clinical scenarios identified in this study indicate that there should be greater HCW clinical discretion allowed. This clinical discretion should consider a mother's personal and social context, her infant feeding decision as well as the Acceptable, Feasible, Affordable, Sustainable and Safe criteria.

These recommendations are aimed at the possible reconsideration of aspects of the infant feeding counselling and guidance offered to mothers living with HIV in order to add to strengthening the HIV prevention of mother to child transmission programme.

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Appendix 1: Participant information Form



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Participant information form

Dear Participant

I would like to invite you to participate in a research study. Please take a few minutes to read the following information carefully – as I would like you to understand why the research is being conducted and how your assistance can impact our understanding for the future.

Research Title

Exploring the guidance regarding infant feeding options provided by Healthcare workers (HCW) to HIV positive mothers of infants 0 – 12 months of age

Purpose of study

This research is trying to understand the knowledge that HCW have about the infant feeding options for HIV negative and HIV positive mothers. It hopes to explore the challenges that HCWs face when discussing these feeding options with HIV positive mothers. With your participation a better understanding of counselling content can be gained as well as provide suggestions that can improve infant feeding practices among women.

This research will be used for a mini-thesis to achieve my Master's in Public Health.

Description of the study and your involvement

The study will include two focus group discussions, the one will contain counsellors only and the second will contain only basic antenatal care (BANC) nurses. Individual interviews will be conducted with medical doctors. Questions about your experiences will guide the discussion in both the FGDs and interviews.

Can you decline or withdraw?

Participating in this study is completely voluntary and you may at any point refuse to participate further. You are also allowed to refuse to answer any question asked with no consequence.

Confidentiality

The records of this study are strictly confidential. Research records will be kept in a locked file, and all electronic information will be stored in a password-protected electronic file. Audio recordings will be deleted on completion of this study.

All information which may lead to your identification will be omitted from the research paper.

Results and benefits

The results of the study will be used to submit my mini -thesis to the University of Western Cape. There are no direct immediate benefits to you, however your participation in this study may guide future guidelines and infant feeding practices.

Questions and concerns

At any point during the interview you have the right to ask questions about the research. These questions will be answered prior to, during or after the interview. If you have further questions regarding the study then you are welcome to contact me, Dr Erin Roberts via email at erinroberts@gmail.com or by telephone at 021 – 360 4200.

If you would like a summary of the of the study results or a copy of my mini-thesis, then please contact me on the contact details below.

Contact details

Researcher: Dr Erin Roberts, MBChB (UCT), DipHIV Man (SA). erinroberts@gmail.com
021 – 360 4200.

Supervisors:

Prof Diane Cooper, dcooper@uwc.ac.za 021 959 2872

Dr Ernesta Kunneke, BSs Dietetics (US), PhD (NWU) ekunneke@uwc.ac.za 021- 959 2760

This research has been approved by the University of the Western Cape's Research Ethics Committee. (BM 19/1/3)

Many Thanks

Appendix 2: Participant consent form



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E-mail: soph-comm@uwc.ac.za

PARTICIPANT CONSENT FORM

Title of Research Project:

Exploring the guidance regarding infant feeding options provided by Healthcare workers (HCW) to HIV positive mothers of infants 0 – 6 months of age

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name.....

Participant's signature.....

Date.....

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office

New Arts Building,

C-Block, Top Floor, Room 28

University of the Western Cape

Private Bag X17

Bellville 7535

Appendix 3: In-depth Interview guide

INTERVIEW GUIDE

Introduction

- Thank you for participating
- Participation and consent form completed
- Confidentiality addressed again

Purpose of interview

- Exploring guidance regarding infant feeding options provided by Healthcare workers (HCW) to HIV positive mothers of infants 0 – 6 months of age.

Basic information

- Qualification (medical doctor)
- Years working in primary health care (experience)
- Experience working with pregnant patients and children
- Experience working in HIV medicine
- Demographic description of the patients accessing their service

Infant feeding policy

- Familiarity with the infant feeding policy
- Previous experience with the infant feeding policy prior to 2011
 - **Probe:** Since 2011 all patients are encouraged to exclusively breastfeed, and formula milk is no longer available for those mothers who would prefer to formula feed

Feelings today

- Advantages of the infant feeding policy
 - **Probe:** ‘breast is best campaign’
- Disadvantages of the infant feeding policy
 - **Probe:** reality for working mothers, migration of young children
- How do you think you patients feel about breast or formula feeding?
 - **Probe:** negative or positive attitudes/beliefs/perceptions

PMTCT policy

- Familiarity with the 2018 PMTCT policy
 - **Probe:** EBF for 6 months, complementary feeding until 24 months. Mixed feeding is not an indication to stop breastfeeding. Only mothers eligible for formula are MDR/XDR mothers in hospital
- Previous experiences with the PMTCT policy – e.g. exclusive formula feeding if HIV exposed
 - **Probe:** telling versus providing option to formula feed in an HIV setting

Feelings today

- Advantages of the PMTCT policy
 - **Probe:** decreased mortality in infants
- Disadvantages of the PMTCT policy
 - **Probe:** What is the risk of HIV transmission in breastmilk

Experiences

- HIV suppressed mother and feeding options
 - **Probe:** What guidance would you offer them
- HIV unsuppressed mother/newly infected in third trimester
 - **Probe:** What guidance would you offer them
 - **Probe:** What additional actions are taken to decrease the risk of transmission e.g. 3 drug PEP?
- Access to formula
 - **Probe:** who can access formula, how do you motivate for formula
- How well do mothers understand that HIV can be transmitted via breastmilk?
- How have you handled these experiences in the past?
 - **Probe:** Have you contacted a tertiary hospital/paediatrician/HIV hotline and asked for guidance?

Challenges faced when counselling mothers on the feeding options

- What influences a mother's feeding choice?
 - **Probe:** Mistrust of the doctors, cultural norms
- Language barrier, accessing health services, work opportunities

- How well trained/equipped do you feel in providing feeding option counselling to these mothers
 - **Probe:** Specify trainings, circulars etc

Feelings today

- Clinical management limited by the policy
- Need to act outside of the policy at times to ensure safety of the infant
 - **Probe:** advice given to purchase formula to ensure no transmission
 - **Probe:** provided formula from the NTP stock
- Do you feel patients can choose their preferred feeding choice?
 - **Probe:** concept of agency
- How could we improve this policy?
 - **Probe:** Should formula be available for certain high-risk groups

Closure

- Questions for the interviewer
- Further observations/opinions/experiences you would like to share?
- Thank you for your participation

Appendix 4: Ethical clearance certificate



**OFFICE OF THE DIRECTOR: RESEARCH
RESEARCH AND INNOVATION DIVISION**

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06 March 2019

Ms E Roberts
School of Public Health
Faculty of Community and Health Sciences

Ethics Reference Number: BM19/1/3

Project Title: Exploring the experiences and perceptions of healthcare workers (HCWs) regarding infant feeding options provided to HIV positive mothers of infants 0-12 months of age.

Approval Period: 15 February 2019 – 15 February 2020

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.


Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

EMREC REGISTRATION NUMBER -130416-050

Appendix 5: Amendment of the 2013 Infant and Young Child Feeding policy: duration of Breastfeeding (H118/2017)



Western Cape
Government

Health

DIRECTORATE: FACILITY BASED PROGRAMMES

Acting Director: Edna Arens

Deputy Director: Hilary Goeiman

Enquiries: Ms NM Henney

Ref: 19/1/2 P

TO: CHIEF DIRECTORS: Metro & Rural Health Districts, Health Programmes, General Specialist and Emergency Services
DIRECTOR: Metro & Rural District Health Services
EXECUTIVE DIRECTOR OF HEALTH: City of Cape Town
FACILITY HEADS: Hospitals
PCGC

ATTENTION: District Directors, MCWH Managers, Nutrition Co-ordinators, HAST and PMTCT Managers

CIRCULAR: H 118 of 2017

AMENDMENT OF 2013 INFANT AND YOUNG CHILD FEEDING POLICY: DURATION OF BREASTFEEDING

Purpose

To communicate the revised infant feeding recommendations following the receipt of the updated 2016 WHO / UNICEF guidelines as received from the National office (Annexure 1).

Executive Summary

The National Department of Health has amended the 2013 Infant and Young Child Feeding policy with regards to the duration of breastfeeding for HIV-exposed babies. The technical update (Annexure 2) includes 2 recommendations and two guiding principles.

Firstly, the recommended duration of breastfeeding for HIV-exposed babies is now extended to 24 months (similar to the general population). Critical to the updated recommendation is strengthened counseling and support for both ART adherence and breastfeeding in facilities and the community. It is still recommended that HIV-infected babies are breastfed for 2 years or more.

Secondly, it is recommended that authorities actively support and coordinate the promotion, protection and support of breastfeeding in health facilities, the workplace, communities and homes.

To facilitate the implementation of the 2 national recommendations the following needs to be addressed:

1. Update the comprehensive Infant and Young Child feeding policy drafted and adopted as Step 1 of the Mother Baby friendly initiative.
2. Update staff (clinical and non-clinical) on the reviewed infant feeding recommendations to enhance breastfeeding knowledge and skills transfer to mothers, caregivers and support structures (father, partner and greater community)
3. Strengthen the support for breastfeeding and informed decision making by implementation of the infant feeding Counseling guidelines (circular HI 66/2012)
4. Strengthen implementation of Step 10 of MBFI by establishing or strengthening the link between Facility Based Services (FBS) and Community Based Services (CBS) to enable the referral of

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postnatal mothers to CBS for home visits, particularly during the first few days after discharge (identified as a vulnerable period for infant feeding practices).

5. Strengthen the link between FBS and CBS with routine postnatal referral of all HIV-exposed babies to CBS for home visits to support breastfeeding and ARV adherence.
6. Healthcare workers must ensure that all pregnant and breastfeeding HIV-infected mothers receive ART, together with adherence support at each visit. Close monitoring of viral load is required in order to reduce the risk of HIV transmission to infants. Ensure that clients understand the purpose of regular VL monitoring. Clients with unsuppressed viral loads must be referred to a medical officer immediately for further management of the mother and to assess eligibility of the baby for PEP.
7. HIV negative clients should have repeat HIV testing at 6 weeks post-delivery and 3-monthly during breastfeeding. Explain and reinforce the importance of retesting to detect new HIV infection during breastfeeding, which carries a high risk of HIV transmission to the infant if untreated. Ask HIV-negative clients to encourage their partners to be tested for HIV.

The two guiding practice statements which should not be used as public health messages but is meant for healthcare workers understanding as noted in annexure 2 are:

Mothers (living with HIV) and healthcare workers can be assured that:

1. ART reduces the risk of postnatal HIV transmission in the context of mixed feeding. Although exclusive Breastfeeding is the recommended infant feeding practice, practising mixed feeding is not a reason to stop breastfeeding.
2. A shorter duration of breastfeeding of less than 12 months is better than never initiating breastfeeding at all.

The aforementioned statement does not alter the current infant feeding recommendation that all women are supported to exclusively breastfeed for six months followed by the introduction of appropriate complementary foods and continued breastfeeding for at least 2 years. Therefore these statements should not be interpreted as endorsing mixed feeding but rather to provide information and reassurance for healthcare staff and clients. These messages also intend to promote extended breastfeeding by women on ART who are unable to exclusively breastfeed or who may only be able to breastfeed for a shorter duration.

Should you require more information or support please contact:

Infant Feeding: Hilary Goeman (tel: 021 483 5663 or email: Hilary.Goeman@westerncape.gov.za) or Nicolette Henney (tel: 021 483 8664 or email: Nicolette.Henney@westerncape.gov.za)

Prevention of Mother to Child Transmission: Jacqueline Vogel (tel: 021 483 0893 or email: Jacqueline.Vogel@westerncape.gov.za) or Dr. Vanessa Mudaly (Tel: 021 483 9986 or email: Vanessa.Mudaly@westerncape.gov.za)

Thank you for your cooperation.



Keith Cloete (Dr)
Western Cape Government: Chief of Operations

Date: 26/08/2017

CC: INP co-ordinators, PCGC's, Provincial Child Health Programme Manager, Womens Health Programme Manager